

THE FEASIBILITY AND EFFICACY OF AN AUTOBIOGRAPHICAL
MEMORY INTERVENTION ON ADVANCE CARE PLANNING
WITH PEOPLE WITH TERMINAL CANCER

by

Cheryl Lynne Brohard

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STATEMENT OF DISSERTATION APPROVAL

The dissertation of Cheryl Lynne Brohard
has been approved by the following supervisory committee members:

<u>Patricia H. Berry</u>	, Chair	<u>4/23/2012</u> Date Approved
<u>Susan L. Beck</u>	, Member	<u>4/23/2012</u> Date Approved
<u>Michael Caserta</u>	, Member	<u>4/23/2012</u> Date Approved
<u>Bob Wong</u>	, Member	<u>4/23/2012</u> Date Approved
<u>Monisha Pasupathi</u>	, Member	<u>4/26/2012</u> Date Approved

and by Maureen R. Keefe, Chair of
the Department of Nursing

and by Charles A. Wight, Dean of The Graduate School.

ABSTRACT

More than 1,500 people die of cancer each day. The majority of people, including those in hospice care, die without a living will, without designating a surrogate decision maker, and without communicating their health-care wishes. To date, education has been the sole focus of facilitating the completion of advance care plans.

The purpose of this exploratory, quasi-experimental study was to test the feasibility and efficacy of a novel autobiographical memory (ABM) intervention to promote advance care planning (ACP) with older persons with terminally ill cancer in hospice care. Using a two-phase study design, data were collected from two independent groups. Data were collected on the ACP outcomes from a control group in Phase 1. Phase 2 introduced the ABM intervention to the experimental group and collected data on ACP outcomes and the ABM intervention.

The findings showed the study was feasible with no attrition by screening with a reliable prognostic tool, accessing data from the electronic medical record, and designing processes and procedures to minimize the challenges and barriers of end-of-life research. Using Mann-Whitney U test, the experimental group, which had received the ABM intervention, had a higher statistically significant likelihood of communicating about the decision for antibiotics ($U(48) = 211.00, Z = -2.83, p = 0.005$) compared to the control group. There was a meaningful trend toward significance with five other variables: decision making about a feeding tube ($U(48) = 231.00, Z = -1.86, p = 0.063$), IV therapy ($U(48) = 203.00, Z = -2.28, p = 0.023$), and communicating about the decision for a feeding tube ($U(48) = 234.50, Z = -2.37, p = 0.018$), blood ($U(48) = 250.00, Z = -1.68, p = 0.094$), and an Out of Hospital Do Not Resuscitate form ($U(48) = 262.50, Z = -2.06, p = 0.039$).

In conclusion, utilizing an ABM intervention may be effective in influencing the decision making and communication of ACP for terminally ill participants with cancer. Further research studies are needed with the ABM intervention and with the ACP Survey, including reliability studies.

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Written by an unknown author but so true for the legacy that this study leaves...Time present and Time past are both present in Time Future.

CHAPTER 1

INTRODUCTION

Statement of Problem

Cancer is the second leading cause of death in the United States; more than 1,500 people will die of cancer each day, and 77% of all cancer diagnoses occur in persons 55 and older, according to the American Cancer Society (2012). The majority of these people, including those in hospice care, will die without an advance directive or declaring their health-care wishes should they become incapable to communicate or make decisions. The discussion and decision making of these end-of-life wishes, including health-care, is known as advance care planning. Advance care planning has been researched as part of the National Institutes of Health end-of-life initiatives. To date, there is no effective educational intervention to facilitate the completion of advance care plans. Recent research findings using autobiographical memories show promise as a means of influencing and directing the future of an individual.

The purpose of this exploratory study was to test the feasibility and efficacy of a novel autobiographical memory (ABM) intervention to promote advance care planning in older people with cancer in hospice care. This was a nonrandomized, quasi-experimental design using a post-test outcome measurement conducted in two phases. In Phase 1, the participants completed the advance care planning (outcome) survey. In Phase 2, participants in group 2 were introduced to the ABM intervention and then completed the advance care planning (outcome) survey. A convenience sample was used for both groups. Fifty (age > 55) people with an oncology diagnosis were recruited from one of the largest hospices in a major metropolitan city in the southwest United States, with 25 people in each phase. In Phase 2, a semistructured, ABM

intervention was used to help study participants recall their memories of family and friends and past experiences with advance care planning and end-of-life decisions pertinent to the participant's present situation.

Aims

The first aim of this study was to test the feasibility (recruitment, adherence, attrition, logistical issues) of recruiting and retaining hospice patients to this type of study and delivering the ABM intervention for advance care planning with people with cancer enrolled in hospice. This study answered the following research questions:

RQ1A: What number and percent of eligible participants will consent, initiate, and complete Phase 1 (survey only)?

RQ1B: What number and percent of eligible participants will consent, initiate, adhere, and attrite to the Phase 2 ABM intervention?

RQ1C: What is the rate of completion for the ABM intervention?

The second aim was to examine the efficacy of the ABM intervention on specific aspects of advance care planning (i.e., do not resuscitate, use of a breathing tube, feeding tube, use of antibiotics, etc.) for people with cancer. This study also answered the following question:

RQ2A: To what extent does the ABM intervention increase the likelihood of decision making and communication with respect to specific aspects of advance care planning (i.e., do not resuscitate, use of a breathing tube, feeding tube, use of antibiotics, etc.) compared to the control group?

RQ2B: What are the remarks reported by participants on the postintervention evaluation interview and the observations of the research team associated with the utility and implementation of the ABM intervention?

Significance of the Problem

Quality end-of-life (EOL) care has been identified as a research priority for the National Institute of Nursing Research (2011), Agency for Healthcare Research and Quality (2011), National Cancer Institute (2010), various hospice and palliative care organizations, professional

organizations such as Sigma Theta Tau International (2012), the Oncology Nursing Society and the American Geriatric Society (Doorenbos et al., 2008; Oncology Nursing Society and Geriatric Oncology Consortium, 2007). Over two decades, research has provided an elementary understanding of EOL and advance care planning. Research shows that hospice patients with short length of stays are especially vulnerable to debilitation, confusion, and disorientation (Stark, Tofthagen, Visovsky, & McMillian, 2012) and thus, there is a need for an intervention that is timely, tailored, efficacious, and feasible with respect to advance care planning while the patient is oriented and able to make health-care decisions. Qualitative research shows people who are diagnosed with a terminal illness desire comfort, dignity, and quality of life at the EOL (Singer et al., 1998). Without advance care planning, the goals of comfort and dignity may be poorly understood and in jeopardy of being honored. In a randomized trial, Ditto and others (2001) found people with advance care plans believed that they had a sense of control over their lives, had more ability to integrate their wishes into the EOL plan, believed that family and physicians would better understand these wishes and honor them, and had a deeper understanding and comfort level with their family. However, projecting an actual EOL situation is difficult for people to conceive until they are in the moment. Decision making that is directed at “in-the-moment” moves the ACP objective from pre-planning for EOL to present EOL situation (Sudera & Fried, 2010).

Autobiographical memory is defined as recalling a memory of one’s life experience (Beike, 2007); it provides a snapshot in time of a unique and highly personal memory. These memories constructed by an individual can be used for the purpose of adaptation or for another specific function (Pillemer, 2003). Bluck and Alea (2009) found ABM serves three functions, including planning for the future or problem solving called directive function, providing a continuity of self called self function, and communicating about oneself called social function. Research has broadened the concept of directive function to include making sense of the past in order to have a coherent view of the present situation and directing future behavior (Bluck, 2003; Bluck, Alea, Habermas, & Rubin, 2005).

EOL can be an amazing, rich learning experience for those who accept and invite others to share in the experience, according to Butler (2007). The EOL journey affords the opportunity to leave a legacy by establishing a tradition of open communication, respect for human dignity, and respect for self-determination in the person's social circle. Many people at the EOL engage in reminiscing about successes and failures, writing their memoirs, and sharing autobiographical memories with family as a means of leaving a legacy or validating their life (Butler, 2007). A unique function of autobiographical memories is to recall a problem or situation that occurred in the past in order to apply what was learned to the present (or future) issue. This function is often called directive (Bluck, 2003). It is this specific function of ABM that was used to create an intervention for the participants that is aimed at recalling their memories of health-care decisions made by others in order for the participants to direct their current health-care decisions in their EOL situation. By remembering the past and learning from their experiences, then the participant can direct his or her current EOL decision making and communication.

The aging of U.S. population and the incidence of cancer in this population will impact EOL health-care decisions and the need of advance care plans. At the present time, there are more than 570,000 Medicare and Medicaid patients who receive hospice care; however, hospice care is the smallest expenditure for Medicare beneficiaries, accounting for 1.2% or \$6 billion of total health-care expenditures, as compared to the largest portion, which goes to the hospitals (NHPCO, 2008). These statistics are expected when few people have advance care plans and/or receive hospice care.

The Baby Boomer generation is the largest generation of U.S. citizens, born between 1946 and 1964, and this generation will affect the face of EOL care as it exists today. As of January 1, 2008, more than 100,000 Baby Boomers turned 62 years old every day for the next 10 years (Associated Press, 2008). By 2030, the American Cancer Society (2012) projects that the elderly population will reach 20% with the incidence of cancer to remain unchanged. Cancer is the most common terminal diagnosis among hospice patients. Approximately 80% of hospice patients are age 65 or older (NHPCO, 2012). A successful intervention for talking about death

and EOL decisions will be paramount as the Baby Boomers age and are diagnosed with life-limiting illnesses.

This study explored the feasibility, efficacy, and effects of an ABM intervention focusing on advance care planning with older persons facing death from cancer. The significance of the proposed study was to provide a reasonable intervention to improve communication and decision making of advance care planning for people with a terminal illness that is congruent with the resolution period at the EOL. The importance of this research study was to lay the groundwork for a future randomized clinical trial using an ABM intervention for advance care planning for people with cancer. The larger significance of this research work is to provide an effective means to improve the completion rate of advance directives.

Overview of Dissertation

The dissertation is arranged into six chapters. This chapter introduces the problem statement, aims, and significance of the problem. Chapter 2 presents a review of the historical and current literature on advance directive and advance care planning, palliative care evidenced based clinical practice guidelines, and autobiographical memory specific to directive functioning. Chapter 3 describes the methods of the intervention study including details of the procedures for the control and experimental groups. Chapters 4 and 5 are presented as manuscripts ready for submission to two different peer reviewed journals. Each chapter is written with the publication criteria for research manuscripts. The chapters include an abstract, background and significance; review of the literature; aims and research questions; methods; data analysis; results; discussion; limitations; implications for nursing; and references. Chapter 4 describes the feasibility, barriers and challenges of conducting hospice study, and actual details of the study design, which corresponds with aim 1 and offers results in conjunction with an analysis and discussion of the finding. Chapter 5 describes the results of the study including quantitative findings and analyses of the demographic and clinical characteristics, the Advance Care Planning Survey, and the two Postintervention evaluations. Chapter 6 includes a synthesis of findings for Chapters 4 and 5,

results not presented in the previous manuscripts, study limitations, implications for practice, future research, theory building, and policy.

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CHAPTER 2

REVIEW OF LITERATURE

Over the past 25 years, research has expanded the theoretical perspectives and practical applications in the areas of autobiographical memory (ABM), reminiscence, end-of-life (EOL), advance directive, and advance care planning. ABM is the theoretical basis for the intervention and is defined as a person's memory of his or her biography of information and personal experiences (Goddard, Howlin, Dritschel, & Patel, 2007). Directive autobiographical memory has been defined as the ability of people to recall personal experiences that have occurred in the past for the purpose of learning or directing the person's future (Bluck, 2003). Advance directive and advance care planning are terms introduced in 1991 and 2003, respectively. Advance directive is a term meaning a declaration of health-care wishes. Advance care planning refers to a discussion of health-care wishes. This study targeted people entering the final stage of life due to cancer and focused on advance care planning.

Advance Directive and Advance Care Planning

The terms advance directive and advance care planning became prevalent in the United States health community after the enactment of the Federal Patient Self-Determination Act (PSDA) in 1990 and the Uniform Rights of the Terminally III Act in 1985 (Olick, 2012; Kass-Bartelmes, Hughes, & Rutherford, 2003). The Federal Patient Self-Determination Act requires that health-care institutions seeking financial payment from a government agency, such as Centers for Medicare and Medicaid Services (CMS), to inform adults of the availability of advance directives (Olick, 2012; Kass-Bartelmes et al., 2003). The Uniform Rights of the Terminally III Act

designated the two legal advance directive documents as the living will and the health-care power of attorney. The living will is also known as a medical directive and serves the purpose of outlining a patient's health-care wishes. The health-care power of attorney, also called a health-care proxy, surrogate directive, or medical power of attorney, serves the purpose of naming a responsible person in charge of health-care decisions (Olick, 2012). These federal acts served as precursors to the laws enacted by individual states, including Texas. Lack of public knowledge about advance care planning and EOL decisions have been well documented in the literature (Temel et al., 2011) and more recently has been reaffirmed during the health-care reform debates of 2009-2011.

In addition to the federal legislation for advance directives are the state statutes, such as the Texas Advance Directives Act (1999), also known as the Texas Futile Care Law. This statute allows a health-care facility to discontinue life-sustaining treatment against the wishes of the patient or health-care proxy 10 days after giving written notice if the continuation of life-sustaining treatment is considered medically inappropriate by the treating medical team (Texas Health & Safety Code, 2009). The Act of 1999 included the passage of the Texas Medical Power of Attorney and the Texas Directive to Physicians and Family or Surrogates to provide a mechanism of voicing a person's wishes or advance directive (Texas Health & Safety Code, 2009).

Research shows that only 20% to 35% of people have some form of advance directive (National Hospice & Palliative Care Organization, 2012). Kierner, Hladschik-Kermer, Gartner, & Watzke (2009) showed that 85% of people with terminal cancer (n = 108) did not desire to enact an advance directive (AD) citing full trust in their physician (22%) and no comment (32%) as the reasons for not making an AD. Researchers and EOL experts (Teno et al., 1997) identified the need for better communication between the patient and family/others; they advised against depending on the advance directive documents to convey the patient's wishes. It was discovered that 65% to 76% of physicians were unaware of the existence of the patient's advance directive (Fried, Bullock, Iannone, & O'Leary, 2009; Quest, Marco, & Derse, 2009). The Federal Patient Self-Determination Act had increased awareness of advance care directive but did little to improve communication between patient and physicians regarding EOL decisions. Dow and

others (2010) reported merely 7% of patients talk with their physicians about their completed advance directive. Lack of knowledge, poor communication, and indecisiveness leads to incomplete advance care planning. Poor communication between patients and their health-care providers and the uncertainty of when to hold the EOL discussions were identified as the major reasons for insufficient communication about advance care planning (Kass-Bartelmes et al., 2003; Dow et al., 2010). Research showed that 43% of women with cancer identified more than one person to serve as health-care proxy, emergency contact, and primary support person, which caused confusion as to who was the health-care surrogate for these women (Dizon, Gass, Bandera, Weitzen, & Clark, 2007). However, having an advance directive (i.e., living will or a medical power of attorney) does not resolve the need for patient communication (Casarett et al., 2010). Caregivers reported that ACP decision preferences were changed at the very EOL when patients with cancer were told that no further treatment would be effective against their disease; caregivers reiterated the need and importance of patient-caregiver open communication to avoid missed opportunities to understand the patient's hopes, fears, desires, and EOL wishes or their advance care plans (Fried & O'Leary, 2009).

The barriers described in honoring patient's wishes include provider non-adherence to the advance directive, inaccessible advance directive, poor surrogate representation, lack of advance directive because patients feel "they are not terminal," and the readability of advance directive with its complicated and confusing instructions (Mueller, Reid, & Mueller, 2010). Those families not accepting the patient's poor prognosis will request treatment against the advance directive (Kirchhoff et al., 2000). Patients and surrogates agreed 61% to 75% of the time when given specific scenarios about prognosis and preferences for end-of-life decisions according to Kirchhoff, Hammes, Kehl, Briggs, & Brown, 2010). Vig, Starks, Taylor, Hopley, and Fryer-Edwards (2007) found communication and decision making were problematic, especially in older people and when the surrogate was not an immediate family member. Like the family or the surrogate, physicians may never know about the advance directive.

Initially, after the Federal Patient Self-Determination Act legislation went into effect, health-care systems put processes and programs in place to meet the requirement of informing

patients of their right to prepare an advance directive (Olick, 2012). Some programs, such as Respecting Choices[®] or Five Wishes[™] serve to educate the patient and family about advance directives (Hoverman, 2011; Maxfield, Pohl, & Colling, 2003) and have been more successful than most. The Gundersen Lutheran Respecting Choices Organization and Community Advance Care Planning Course was developed to establish an EOL community standard in LaCrosse, Wisconsin by using a systematic approach to advance care planning using video, materials, and trained personnel. This program was offered to the city's major health-care institutions, and the Gundersen Lutheran Foundation (2008) reported that 85% of people who died in those institutions had advance directives after 2 years of implementation. The popular program 5 Wishes[™] is an initiative to promote EOL communications, including who makes health-care decisions when the individual cannot make decisions, the kind of medical treatment the individual wants or does not want, how comfortable the individual wants to be, how the individual wants to be treated, and what the individual wants "his or her loved ones to know" (Maxfield et al., 2003). Five Wishes[™] was the result of Jim Towley's personal experiences with EOL care and his work with Mother Teresa. These two programs are offered to the public for a fee by their respective non-profit organizations.

The Internet also offers education through several grant-funded projects for the purpose of educating the public on advance directives. Representative projects, such as Caring Connections, Put It In Writing, Last Acts, and Caring Conversations, are summarized in Table 2.1. These projects are aimed at providing the public with information on EOL statistics and resources, such as the advance directive, the latest legal forms by the state, and downloadable questionnaires and helpful information. There is no evidence that research has been done to evaluate the effectiveness of these programs or their resources.

Other advance directive research focused on the health-care provider, and those that were best suited for discussing advance care planning—a staff nurse (Cohen & Nirenberg, 2011; Jezewski, Meeker, & Schrader, 2003; Lipson, Hausman, Higgins, & Burant, 2004), nurse practitioner (Sessana & Jezewski, 2008), social worker (Black, 2006; ONS, 2010), or physician (Hoverman, 2011; Sahm, Will, & Hommel, 2005). The findings showed that the task of

communicating prognosis was best given by the physician, but the other health-care professionals could provide valuable information and resources that were needed by the patient and family. Further research has been directed at what specific settings are most appropriate, including dialysis (Miura et al., 2006), nursing homes (Buchanan, Barkley, Wang, & Kim, 2005), hospitals (Hoverman, 2011), and the community (Santiago, 2005), but no research has been done at a hospice. The results of these studies concluded that more research is needed with patients and families to explore what works and what does not work in a specific setting. Ethnic, social, and age-specific research for advance directives also exists and includes analysis of Mexican Americans (Santiago, 2005), African Americans (Welch, Teno, & Mor, 2005), Asian Americans (Dang, 2005), Asian Indian (Sharma, Khosla, Tulsky, & Carrese, 2011), and the elderly (Ditto et al., 2003; Hamel, Guse, Hawranik, & Bond, 2002; Witte, Menon, Ruskin, Wiley, & Hebel, 2003). This research found that family culture and patient's personality played a role in communicating, decision making, and executing an advance directive.

Singer et al. (1998) developed the first Advance Care Planning Process Model (Figure 2.1) based on qualitative responses from 48 patients undergoing hemodialysis who were interviewed six months after the education. The model depicted two processes of interaction for the patient: communication with the surrogate decision maker (i.e., family and friends) including their responses, and the patient's action of enacting of an advance directive (i.e., living will) secondary to decision making. In their research, Singer and colleagues (1998) identified an initial antecedent as an event (e.g., death of a close friend or family), realization of mortality, or life-threatening diagnosis (e.g., cancer), and the advance directive education as a precursor to advance care planning. Communication between patients and their families and their response was crucial in this process. The individual's advance care planning actions are independent of his or her family's response, meaning that the patient can make decisions with or without the family's knowledge and can choose to communicate or not communicate these decisions to his or her family.

The lack of advance directives continues to be a problem in the United States. There is little improvement in the completion rate of advance directives despite education, research,

creation of complex systems aimed at resolving the issue, and mandatory questioning in health-care settings. No research studies with advance directives or advance care planning were found in the literature review associated with the hospice setting. This study will provide information on the percentage of people with terminal cancer electing hospice who have advance directives.

Palliative Care Evidence-Based Clinical Practice Guidelines

Two sets of guidelines were found that are pertinent to this study. The Palliative Care Clinical Practice Guidelines in Oncology (V.1.2009) developed by the National Comprehensive Cancer Network (NCCN) are the recognized standard of care in oncology and provide the latest evidence-based practice recommendations based on an established level of evidence and consensus. When a person has a life expectancy of weeks to months, the implementation steps of advance care planning include determining preference for the following: cardiopulmonary resuscitation (CPR), mechanical ventilation, nutrition/hydration, blood products, antibiotics, and dialysis. Advance care planning also includes seeking resolution of conflicts, ensuring that these wishes are known to the family, exploring fears of dying, and understanding desire for organ donation (p. PAL-24). A successful completion of the recommended tasks may result in adequate ACP, reduction of patient/family distress, acceptable sense of control, relief of caregiver burden, strengthening relationships, optimal quality of life, and personal growth and meaning (p. PAL-25).

The Clinical Practice Guidelines for Quality Palliative Care, Second Edition (2009), identified that physical, psychological, social, spiritual, religious, and existential aspects of care are among the eight domains of palliative care. A life review is noted as a means of exploring the spiritual and existential concerns of the individual but not as a tool for advance care planning. There is no empirical research published in the literature with palliative care guidelines and autobiographical memory or life review since their origin in 2004. This raises the question why the proposed study uses an ABM intervention, which is addressed in the next section.

Autobiographical Memory

From a practical perspective, it is easy to confuse the concepts of autobiographical memory and life review. Autobiographical memories are snapshots in time of unique and highly personal life experiences (Beike, 2007). The following section explores the theoretical perspective of the directive function of ABM including the historical development, hierarchy of ABM types, problem solving, and participant characteristics that are and are not statistically associated with successful ABM recall. Lastly, the section differentiates an autobiographical memory from life review.

Historical Developments in Directive ABMs

ABM has been empirically studied for the past 15 years with the most recent research focused on the utility of memory in everyday life. Evidence supports the theoretical perspective that various functions of ABM exist, including the directive function of ABM (using past experiences to problem solve present-day issues) having relevance to social problem solving with a variety of populations and social issues. Research findings show the likely participant response based on the hierarchical organization of ABM and the suitability of the intervention from the characteristics of the participants such as age, gender, and cognition. Directive functioning studies have been comparatively consistent with the use of the Means-End Problem-Solving Task instrument developed to measure the outcomes of ABM. This study proposed the use of ABM as means to facilitate the discussion on health-care decisions, which is a variable included in the decision-making process of EOL.

Historically, the directive function of ABM has been less prominently theorized and researched than self or social function (Hyman & Faries, 1992; Nelson, 1993). Goldsmith and Pillemer (1988) reported that statements made by parents to provide advice or guidance are examples of directive ABM. In more recent years, ABM and lifespan researchers have used qualitative and quantitative approaches with various populations to establish the link between social problem solving and the directive function of ABM. Pillemer (1992) used problem solving to gain confidence to complete a task or to develop opinions and attitudes. Pillemer (2001)

described the social problem solving used by an adolescent to overcome her reluctance to talk at her parents' high school reunion as an example of the directive function. Pasupathi, Lucas, and Coombs (2002) coded married couple's conversations and found that ABM of past events were frequently recalled for the purpose of problem solving, planning, reminiscing, evaluating an event, oneself, or one's partner, and explaining oneself, thus using the directive function of ABM. McLean and Thorne (2003) explored young adults for self-defining moments for meaning making and found 40% of the memory narrative includes references and lessons learned or insight gained from these moments. A focused episode of autobiographical memory from college was used to influence the intention and decision making of philanthropic activity with university students (Kuwabara & Pillemer, 2010). Pillemer (2003) drew attention to the importance of the directive function of ABM with his work on traumatic memories. He said that the role of memory in human adaptation and problem solving of past experiences emphasized the evolutionary significance and practical importance of directive function memories.

One study provides the most compelling evidence that adaptation occurs after a death-related experience. The study was conducted with 52 hospice volunteers, age ranged from 20 to 86 years, comparing a novice group to hospice to a more experienced group of hospice volunteers (Bluck, Dirk, MacKay, & Hux, 2008). The research found more frequently remembered real-life experiences with death as a hospice volunteer was associated with lower levels of death anxiety and avoidance. Participants reported that death-related memories of an actual death experience were adaptive or directive in nature using the Thinking About Life Experiences (TALE) questionnaire (Bluck et al., 2005). These experiences were reported as a landmark or momentous event (Pillemer, 2001) that altered the volunteers' lives from that point forward. The hospice volunteers (57%) found benefit in the death-related memory narratives that were written regardless of how many months or years the experience had occurred (MacKay & Bluck, 2009).

Hierarchical Memories of ABM

Williams and Dritschel (1992) identified a hierarchy within ABM consisting of specific and general memories. Specific memories are constructed with precise details, such as person, place, and time, and are positioned at the bottom of the hierarchy. At the top of the hierarchy are general memories. General memories fall into two types: categorical memories describe multiple occurrences of the same event, and extended memories describe events occurring over a period of time, which were also called lifetime periods by Conway and Bekerian (1987).

Williams et al. (2006) examined the mechanism of this hierarchy of ABM in a study where participants were instructed to be specific about a highly visual image (e. g., nun) and an abstract word (e. g., malice). Results showed statistical significance ($p < .001$) for participants who retrieved more specific memories following “be specific” instructions and for the highly visual cue words than for participants following “be general” and when cues were abstract. Deliberate prompting of ABM (Conway & Pleydell-Pearce, 2000) with questions was the impetus for the development of an instrument to quantitatively differentiate between specific memories and general memories.

Problem Solving with Directive ABMs

Through a series of studies since mid-2000s, there appears to be an association between the retrieval of overgeneral autobiographical memories and an ineffectiveness of ability of a person to problem solve (Kaviani, Rahimi, Rahimi-Darabad, & Naghavi, 2011). Williams (1996) hypothesized that people with traumatic brain injury with a co-morbidity of clinical depression would retrieve less specific memories and have a decreased ability to problem solve. Williams, Barnhofer, Crane, and Beck (2005) found people with a history of clinical depression with and without suicidal ideations had a greater loss in the Means-End Problem-Solving Task test relevant means scores and problem solving effectiveness as compared to the control group for before and after a mood-induced challenger. Kuyken, Howell, and Dalgleish (2006) studied ABM in relation trauma, depression, and the number of recalled overgeneral memories (i e., lacks any specificity) using a group of 62 adolescents divided into three groups. Adolescents with no

trauma and diagnosed with depression recalled the greatest number of overgeneral memories, followed by adolescents with trauma and depression, followed by the control group with no depression and no trauma. Arie, Apter, Orbach, Yefet, and Zalzman (2008) compared 75 adolescents and young adults with suicidal ideations with nonsuicidal thoughts and a health control group. The nonsuicidal group and the healthy control group had higher relevant and efficiency means on the Means-End Problem-Solving Task test and lower general memories compared to the suicidal group, thus supporting Williams' original theory of depression affecting the ABM and problem solving. These studies show that people with traumatic brain injury, clinical depression, and suicidal ideations are less likely to recall specific autobiographical memories and have decreased problem solving. Based on these findings, this study will exclude people with the cognitive inability to engage in the intervention or people clinically diagnosed with dementia, Alzheimer's disease, or clinical depression.

It is theorized that problem solving requires a high capacity of working memory in order to accomplish more than one thing at a time; specific memories provide a compilation of rich details needed for problem solving. Evans, Williams, O'Loughlin, and Howelles (1992) created 10 scenarios to retrieve a specific event and solve a hypothetical social problem leading to the development of the Means-End Problem-Solving Task instrument. The solutions to the scenarios are coded for relevant means (detailed steps or ways of solving the problem) and for the ends (effectiveness of the solution or how well the solution met the goal). Goddard, Dritschel, and Burton's (1997) research supported the theory that specific memories provide the means to define and understand present problems and generate solutions as tested by Means-End Problem-Solving Task instrument. The Means-End Problem-Solving Task instrument has been repeatedly tested for inter-rater reliability, reliability of content, and validation of problem solving relevant means and effectiveness with adults of all ages enrolled in ABM research including control groups (D'Zurilla & Maydeu-Olivares, 1995; House & Scott, 1996).

These data support the link between specific memories and problem solving as measured by the Means-End Problem-Solving Task instrument. Using a detailed script with highly visual and familiar cue words and a single facilitator for the intervention are associated with

improved retrieving of ABM. Higher levels of relevant means and greater effectiveness of problem solving are participant outcomes of using a script with an introductory explanation of ABM, clear instructions on being specific with their memory recall, and cueing or prompting for more details if the participant was recalling general memories. Based on these findings, the ABM intervention was designed to include procedures and processes that will enable the older adult participant to be successful.

Participant Characteristics with ABM

It has been argued that there are gender-related, age-related, and cognition-state differences in ABM and social problem solving. Research on social problem solving and ABM led Goddard et al. (1998) to use three conditions (i.e., single task, easy dual-task, and a difficult dual-task) in retrieving memories to study gender differences. They reported no difference in gender in retrieving ABM for social problem solving using Means-End Problem-Solving Task instrument for 30 male and 30 female college students. However, females in a single task condition generated more relevant means (details) than females in the easy dual-task group ($p < .0001$) or the difficult dual-task group ($p < .001$) or males in a single task condition ($p < .001$). Researchers found males generated about the same relevant means for the three task conditions, and the effectiveness of solution was virtually the same for gender and for the three task conditions. Based on the programs of research of Williams, Goddard, and Bluck, there is no difference in gender; however, Goddard and others (1998) found that male and females have the ability to retrieve more specific memories for problem solving in a setting with minimal distraction where participants can give their full attention to the posed questions.

In a study conducted by Beaman, Pushkar, Etezadi, Bye, and Conway (2007), they found inconclusive evidence that age-related differences in ABM and problem solving as linked to cognition. They compared 40 older participants, ages ranged from 61 to 83 years, and 40 younger participants, ages ranged from 19 to 25 years, to investigate age-related declines in cognitive ability predicting less specific ABM of recent events. Using hierarchical regression analysis, this study found that age, health, and education explained 10% of the relevant means of

the Means-End Problem-Solving Task instrument ($p < .05$), with health being the influential variable; adding the cognitive factor did not explain significant variance; and adding specific memories explained another 12% of the variance of the relevant means of the Means-End Problem-Solving Task instrument ($p < .01$). The researchers reported that this study supports the theory that ABM serves as a directive function across the lifespan regardless of age and strengthens the evidence that cueing in the intervention enables the retrieval of more specific memories to be generated for present-day social problem solving.

Goddard and others (2007) found no difference in retrieval and effectiveness of ABM and social problem solving in 44 adults between the age of 18 and 35, with and without Asperger Syndrome. Adults with Asperger Syndrome have difficulties with social interaction while being cognitively sound. This study showed no difference in the ability to describe specific memories using ABM for problem solving between the experimental group and the control group.

Age, gender, and cognitive soundness are important findings in considering participant eligibility criteria for this study. The ABM intervention focused on the specific memories of a single episodic event, the lessons learned from that experience, and how these ABM can help in the participant's present-day situation. Episodic events are personal in nature with vivid sensory-perceptual-affective information and involve a specific event oriented to a person and to a time (Conway, 2001). For this study, the episodic event was constructed memories from the participant's perspective. The elicited episodic ABMs that were recalled were socially constructed from the participant's past experience. While accuracy of the ABM is important, Meacham (1995) reported that individuals witnessing the same event will have a distinct individual perspective based on their socially constructed memory and experiences. However, participants with cognitive impairments will be excluded from the study. The participant must be able to recall a memory and engage in problem solving to be considered as part of a directive intervention using ABM. Exclusion criteria established for participation in this study will be the inability to recall a memory due to cognitive abilities, an inability to focus due to symptom intensity, or an inability to process thoughts due to a decline in the functional status due to disease progression.

The directive function of ABM is helpful from the standpoint of not repeating a mistake, changing one's life, or gaining insight into a situation. The death or the memory of an immediate or close family member's death is considered a life-changing event on many levels and can be described as a turning point in one's life or a momentous event that influences all future events. Cappeliez, Beaupre', and Robitaille (2008) described these events as turning points because a new path is taken that alters the person's future and life course. Pillemer (2001) described the momentous event as a salient event that influences or alters a person's life story. Pillemer's (1998) example of a momentous event was the terrorist attack on September 11th (9/11) in the U.S. This life-changing event (9/11) changed the paradigm of travel across the globe. It is theorized that these positive or negative, remarkable, life-altering moments or events will be revisited at intervals throughout our lifetime in memories or stories we tell to others.

Rasmussen and Berntsen (2009) asked 120 participants, 18-33 years old, to recall a directive function, self-function, social function, and a control memory. Participants were cued to recall directive memories that would help handle a present or future situation. They found 53% of directive-memories were categorized as a stressful event, death/funeral, or an accident (injury and illness). Directive memories were more consequential in the participant's life than self- or social memories ($p < .05$) and had longer verbal responses than self- or social-memories ($p < .05$).

Conclusion

In conclusion, ABM has been extensively researched with evidence that a direction function serves as a means of adapting and problem solving. Directive function has not been substantiated as an intervention at the EOL but has been researched as an adaptive function with hospice volunteers. This study will examine the use of an ABM intervention for a directive function with participants enrolled in hospice. The literature supports that an ABM intervention can be a viable method of problem solving.

The literature review of advance care planning and autobiographical memory from the previous 15 years provided critical information to consider in proposing the methods of this research study. In summary, enacted legislation, health-care education for providers and

patients, community-based programs about ACP, and evidence-based clinical practice guidelines have done little to improve the completion rate of advance directives. Autobiographical memories used in a directive function have shown promise in influencing the current situation from past experiences. There is a gap in research for autobiographical memory related to ACP. This study hopes to fill the gaps in research related to the feasibility of an autobiographical memory intervention for ACP with terminally ill people with cancer.

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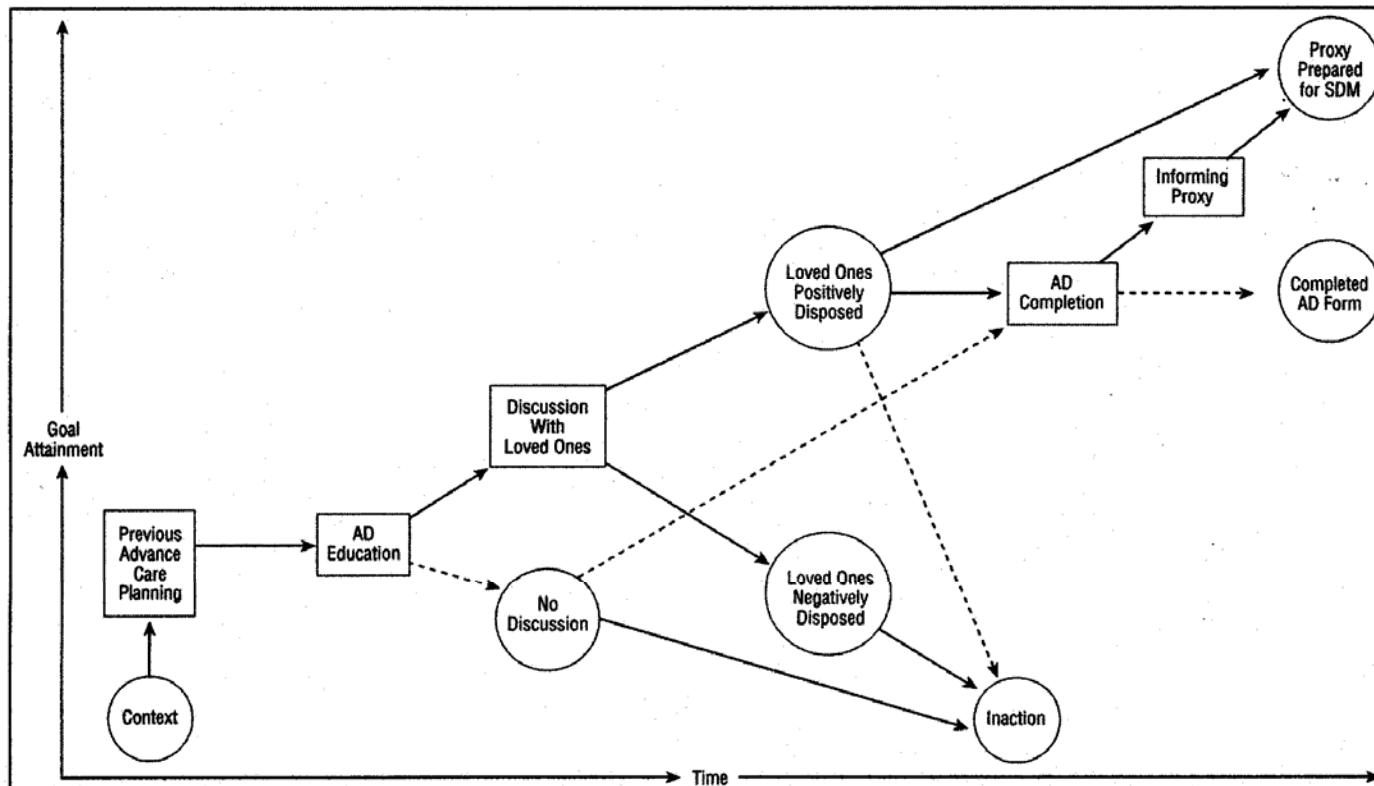
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The process of advance care planning represented visually. Squares indicate events; circles, states; solid lines, common pathways; dashed lines, uncommon pathways; AD, advance directive; and SDM, substitute decision making.

Figure 2.1. Advance Care Planning Model (originally developed by Singer et al., 1998) and published with permission from Dr. Singer.

Table 2.1 Advance Care Planning Education Resources

Program name	Summary of the program with web site
Center from Practical Bioethics Guidance at the Crossroads of Decision	This initiative promotes meaningful discussions about EOL decisions between individuals and their families. Caring Conversations® is a registered trademark for this program. The Center and the Kansas City Regional Ethics Committee published a 41-page book called Recommended Policy Guidelines Regarding Medical Futility. Web site: http://www.practicalbioethics.org/cpb.aspx?pgID=886
Caring Connections	This is a program created by the NHPCO and supported by the Robert Wood Johnson Foundation to improve EOL care. This Web site has the most current AD documents downloaded for no fee. It's About How You Live is a cooperative program with local, state, and national level partners. Web site: http://www.caringinfo.org/
Put It In Writing	The American Hospital Association's initiative encourages people to write down their AD. A brochure with basic information on AD and a wallet card are available. A public-service advertisement that can be modified for communities or organizations. Web site: http://www.putitinwriting.org/putitinwriting_app/index.jsp
Aging with Dignity	The popularized program 5 Wishes™ is an initiative to promote EOL communications, including designated surrogate, desire for medical treatment, comfort level, treated, and loved ones to know. There is a charge. Web site: http://www.agingwithdignity.org/5wishes.html
Respecting Choices®	This is a program focused on providing education and resources to health-care professionals for the purpose of improving EOL communications. Gundersen Lutheran health-care system in LaCrosse, Wisconsin, is the sponsor of this program and charges for training. Web site: http://www.gundluth.org/eolprograms
Last Acts	The Robert Wood Johnson Foundation supported this Web site to improve and enhance quality EOL care. The Web site is an archive of white papers, resources, and links. Web site: http://www.lastacts.org will be redirected to http://www.rwjf.org/newsroom/feature.jsp?id=20938&typeid=151

Note. This is not a complete list of advance-care planning resources.

CHAPTER 3

METHODS

Overview of Study Design

This was an exploratory, quasi-experimental study designed to test the feasibility and efficacy of a novel ABM intervention to promote ACP with older persons with terminally ill cancer in hospice care (Figure 3.1 Study Design). There were two phases of this study and two separate and independent groups (i.e., control and experimental). In Phase 1, data were collected on the ACP outcomes from the control group. In Phase 2, the ABM intervention was introduced to the experimental group and then data were collected on the ACP outcomes, which were decision making and communication. By design, Phase 1 was completed in its entirety before participants were accrued to Phase 2; thereby, participants in Phase 1 were not eligible for Phase 2. Because of the potentially sensitizing nature of the ACP Survey, the two-phase study was accepted as a means of preventing a confounding threat to internal validity that most likely would occur with the instrument. Phase 1 consisted of screening, enrollment, consent, and outcome measurement (ACP Survey); in comparison, Phase 2 added the ABM intervention and additional outcome measurements to evaluate the ABM intervention.

Research Site and Setting

Houston Hospice is the oldest hospice in Texas, established in 1980 as an independent, non-profit, freestanding hospice, and serves adults and pediatric patients with terminal illness in 10 counties. The mission of the Houston Hospice is to provide uncompromising, compassionate EOL care to patients and families in the community, which includes approximately 2,000 admissions annually, accounting for an average daily census of 210 patients. Approximately 90%

of the adult patients enrolling into this hospice were 65 years and older. This study recruited adults enrolled in home hospice with a cancer diagnosis.

A hospice home team delivered care to patients who resided in a home, an assisted living facility, or a nursing home. Each of the four hospice home team consisted of a patient care manager who was responsible for the delivery of patient care by the interdisciplinary team within a specific key map region. The interdisciplinary team consisted of the medical director, RN case manager, licensed vocational nurses, home health aides, social workers, chaplains, bereavement counselors, and volunteers. The hospice adhered to regulations of privacy and confidentiality as defined by the state of Texas. The hospice was accredited by the Community Health Accreditation Program, Inc.

Sample

A convenience sample was recruited from the home hospice teams. Sample size was determined by the number of participants for the desired power based on a significance criterion and the effect size (Cohen, 1990, 1992). An a priori power analysis was used to calculate the sample size using G*Power Version 3.1.0 software program (Faul, Erdfelder, Lang, & Buchner, 2007). To determine a difference between two independent groups using t-test, this study was based on an alpha of 0.10, power 0.80, and medium to large effect size (Cohen's d) of 0.70. The a priori alpha level was set at 0.10, which was a reasonable level to determine if the intervention made a difference as compared with the control group in a feasibility study (Bartlett, Kotrlik, & Higgins, 2001). The observed clinical effect was important to determine the utility of this novel intervention study on ACP; a medium to large effect size was set for this study (Dupont & Plummer, 1990). Based on these parameters, the pilot feasibility study had a total of 50 participants with 25 participants accrued in each phase of the study.

Based on information obtained from the hospice, the patients cared for by the home teams of Houston Hospice were homogenous with respect to their terminal diagnosis of cancer, age, and average length of survival in days. To maximize the eligible patients for enrollment, all four hospice home teams were used as referral sources. The participants in this study were

defined as the persons with a primary cancer diagnosis with a life expectancy of less than six months. Patients living in their home including an independent or assisted living facility were eligible (see Table 3.3 Study Eligibility for Participants). Study participation was open to all genders, racial/ethnic groups, socio-economic classes, and educational levels. Enrollment was voluntary, and participants could have discontinued their participation at any point in the study.

Recruitment

Recruitment for Phase 1 started with each patient care manager and the medical director of the home teams; they were asked to identify patients meeting criteria for the study. The PI provided an overview of the study, including purpose, background, eligibility criteria, and procedures for enrollment. From that point forward, the PI screened all new admissions to hospice to ensure that study criteria were met; electronic medical records were available to the PI for screening and recruitment purposes. When the patient met criteria, the PI asked the Quality Assessment (QA) assistant to contact the patient for consent for enrollment.

The PI provided a handout explaining the study to the QA assistant. A study announcement was made at the management meeting, and the attendees were updated as accrument progressed. These announcements were approved by the University of Utah Institutional Review Board (IRB) and the Houston Hospice Ethics Committee.

Consent

The same procedure was used for both phases of this study to minimize the threats of internal and external validity. The QA assistant would telephone the patient and email the PI the outcome of the conversation. If the patient agreed, then the PI scheduled an appointment with the patient between Day 5 and 9 after admission to explain the study and obtain informed consent and signatures. The PI confirmed the demographic and clinical information from the medical record and during the patient interview. All patients were screened by the PI prior to enrollment in the study, including reviewing the demographic and clinical data from the referral source. Those patients not meeting eligibility criteria were offered the organization's resources

for ACP and genuinely thanked for their interest in the study. Those patients who elected not to enroll in the study were asked their reasons for not enrolling. Reasons for not enrolling were important information to know for a feasibility study. Participants were removed from the study if they withdrew consent, were too ill to continue, or died; however, no participants had to be removed from the study. Eligibility criteria were met before the participant was approved for the study (Addendum A, Advance Care Planning Study Screening Checklist).

Prior to the study, the PI estimated that the ABM intervention would take 60-90 minutes. An alternative control condition for the control group was developed in order for the control group to receive approximately the same amount of support and attention from the PI as the experimental group. The PI spent time with the control group asking questions about their cancer trajectory including diagnosis, workup, treatment, doctors, cancer clinics, and follow-up tests prior to their admission to hospice. The PI did not ask or involve ABMs of ACP. All participants received the PI's contact number for any questions or concerns.

The PI gave full disclosure by reviewing the consent form and reading it to participant if requested. The participant was asked for his or her consent and signature on the approved consent forms. A copy of the consent forms was given to the participant, and the other copy was filed in his or her study record. The IRB approved two separate consent forms for each phase of this study. No crossover participants and no randomization were allowed in this study. The three main differences between the consent forms were the addition of the autobiographical memory intervention on Phase 2 consent, the risks associated with remembering experiences of end-of-life, and an evaluation of participants who agreed to answer some questions about the ABM intervention.

Procedures for ABM Intervention

Phase 2 began immediately after Phase 1 was completed. Signatures were obtained on the consent forms similar to Phase 1. The PI planned to have as many ABM sessions as it took to complete the intervention checklist (talking about memories of family and friends who have died and their health-care decisions at the end of their lives); however, only one visit was needed.

The ABM session and evaluation were completed within a 1 week time period as it was important to complete the ABM intervention checklist (apart from the amount of time or number of sessions it takes) to ensure rigorous procedures were kept and there was no issues with internal validity. Each session was timed and limited to 90 minutes to avoid participant fatigue. The PI conducted the ABM intervention sessions. It had been planned to tape record these sessions, but there were technical and mechanical problems and tape recording was abandoned. A voice-activated recording system sensitive to voice range, pitch, and tone was needed to pick up soft voices and whispers.

The PI was responsible for adhering to the talking points as outlined (see Addendum B, Checklist for Study Screening through Closure). Logistically, the PI answered all study questions, tracked session times, recorded the sessions with field notes, and maintained supplies to ensure efficient process. As part of the feasibility, the PI tracked the length of the intervention, the topics, the ease of conducting the intervention, participant questions, and how to encourage the participant to provide more detail, including the amount of pre-intervention data needed to assist in the processes of the intervention.

The ABM intervention consisted of open-ended questions and talking points to encourage the participant to recall past memories and experiences of family members and friends who have died and the participant's memories with advance care planning and end-of-life decisions. For example, the PI introduced the ABM intervention by explaining in common language that memories are constructed from social situations, and our memories of these experiences may help us make a decision on a personal level related to our own EOL wishes and communicate these decisions to our family members. Prompts and probing verbal and nonverbal cues, such as nods or phrases like "tell me more," were part of the intervention to encourage ABM details. The sequence of questions moved from global and less threatening to deeper and more sensitive questions. The sequencing from general to specific was aligned with the hierarchical perspective of ABM and enabled the PI to form a bond with the participant, allowing the participant to feel comfortable disclosing personal information and enabled the PI to pace and adjust the intervention from the feedback of the participant.

The PI recognized that memories from one's past experiences of EOL and one's present experience could be upsetting to the participants if they were struggling with the meaning of life or death. The PI anticipated that these memories might have been emotionally charged for the participants as they deal and cope with their own EOL. Psychological, social, and spiritual counselors, available resources, and services at Houston Hospice were to be offered to the participant; however no such intervention was needed.

Procedures for Measures and Instruments

The operational definitions for the study dependent and independent variables are presented for review (Table 3.3, Defined Dependent, Demographic, and Clinical Variables). Demographic and clinical data were collected by the PI from participants and the medical record as part of the enrollment process; these variables were considered independent. Decision making and communication are ACP constructs that were measured as the dependent (outcome) variables using the Advance Care Planning Survey. The Demographic and Clinical Information Survey variables are outlined in Tables 3.3 and 3.4. A Postintervention Evaluation Interview for the ABM intervention (Addendum C, Postintervention Evaluation Interview for ABM Participants) was completed over the telephone with participants who completed Phase 2 of the study and agreed to participate in the evaluation interview.

The Advance Care Planning Survey was constructed from the research findings of the NCCN Palliative Care Guidelines (V.1.2009), the Agency for Healthcare Research and Quality Advance Care Planning: Preferences for Care at the End of Life publication (Kass-Bartelmes, 2003), and the 2008 NHPCO Facts and Figures on Hospice Care in America. A group of experts within the hospice reviewed the survey for its content and face validity (Frank-Stromberg & Olsen, 2004; Polit & Beck, 2003); the survey was further refined and validated by the experts on the dissertation committee. The ACP Survey was pilot tested with three people diagnosed with cancer with no recommended modifications (Addendum D, Advance Care Planning Survey).

The outcome measurements were collected by the research nurse using an interview over the telephone. This type of format had been successfully used in other intervention research

with oncology patients (Mooney, Beck, Friedman, & Farzanfar, 2002; Barsevick et al., 2004). These data were collected between Day 10 and Day 13 after admission to hospice. The checklist for each phase was followed by the PI (Addendum B Checklist for Study Screening through Closure). The PI reminded participants that a \$10 gift card and a letter of appreciation for enrolling in the study would be mailed to their home (Addendum E, Thank you Letter for Study Participation).

Current Admission Procedure

The hospice Admission RN provided the usual and customary education about advance directives through an information session or the admission process. As part of the information session, the nurse asked if the following legal documents have been completed: a living will, the medical power of attorney, and the OOHDNR Order form. The admission packet included an explanation of each of these documents. If the patient desired to execute an OOHDNR, then the Admission RN facilitated the completion of this or these documents. If the patient wished to enact a living will or medical power of attorney, then the patient was directed to the educational materials, and the social worker was consulted to help the patient execute these documents. The living will and medical power of attorney are legal documents and must be drawn up by a legal representative to be deemed official by the state of Texas.

Research Team

The research team consisted of the PI, QA assistant, and a research nurse. The PI was responsible for the oversight of study operations, quality integrity, and study completion. The PI conducted the ABM intervention session. The PI ensured the integrity of the study intervention by using a checklist and adhering to the study script and procedures. Early corrective action was important for maintaining the study's integrity. Periodic checks by the PI ensured the integrity of the intervention throughout the study. The research nurse was responsible for administering the ACP Survey to both control and experimental groups and for conducting the postintervention evaluation interview. The research nurse was a registered nurse in the state of Texas with

previous hospice experience and clinical research experience at The University of Texas M. D. Anderson Cancer Center.

Data Management

Data were managed through three software programs. The initial screening data was collected in a Microsoft Excel document as this included all new patients enrolled into the hospice program. For candidates that were approached for enrollment, the PI entered data into REDCap, a secure, web-based application for building and managing online databases, used at The University of Utah, College of Nursing (Harris et al., 2009). Data from the REDCap database were exported to SPSS version 20.0 for final statistical analysis. Using an Excel document, the PI tracked study progress including screening, demographic and clinical data, consenting, intervention, and evaluation. The PI performed extensive validity checks on the data looking for missing data, outliers, errors in data entry, inconsistencies using frequencies, and box plots as well as evaluating for skewness or kurtosis in SPSS. Files were duplicated and saved in REDCap; this process ensured safety of the original database.

Data Analysis

The data were analyzed with using Statistical Package for the Social Sciences (SPSS) version 20.0 for graduate students. The PI was responsible for data management, including data entry, data accuracy, and data integrity. The PI and the research nurse performed an analysis to ensure that data were accurate in the REDCap system. Frequency distributions were run on a bi-weekly basis to monitor screening, enrollment, and attrition during Phase 1 and Phase 2. The database was monitored to check accrual numbers for each phase of the study. When the study was closed, there was a comprehensive review of the data points. Table 3.2, Design Schema depicted the overall plan that was used for data analysis.

The first aim of this study was to test the feasibility (recruitment, adherence, attrition, logistical issues) of recruiting and retaining hospice patients to this type of study and delivering the ABM intervention for advance care planning with people with cancer enrolled in hospice. For

Research Question 1A: What number and percent of eligible participants consented, initiated, and completed Phase 1 (survey only)? Descriptive statistics (frequencies) were used to describe the participants in the control group including demographic and clinical characteristics. A flowchart of recruitment, enrollment, and attrition was created from Phase 1 that included the number and percent of patients screened, enrolled, dropped out and those who completed the study. Demographic and clinical information were reported for participants completing the study included age, gender, diagnosis, etc.

For Research Question 1B: What number and percent of eligible participants consented, initiated, adhered, and dropped out in Phase 2 ABM intervention? A flowchart of recruitment, enrollment, and attrition was created from Phase 2 data including the number and percent of patients screened, enrolled, dropped out and completed the study. Descriptive statistics (frequencies and graphical displays such as histograms and box plots) were used to describe the number of people:

- Screened for eligibility, met inclusion criteria, met exclusion criteria, and why ineligible
- Recruited for the study, not approached for recruitment and why, consented, and not consented and reason
- Adhered to ABM intervention instructions (i.e., the number of participants that had to be redirected back to the ABM intervention)
- Attrition and reason (expired, too ill to complete, dropped out, or excluded).

For Research Question 1C: What was the rate of completion for the ABM intervention? Descriptive statistics (frequencies) were used to describe the number of people who successfully completed the ABM intervention including demographic and clinical characteristics in the experimental group.

The second aim of this study was to examine the efficacy of the ABM intervention on specific aspects of advance care planning (i.e., do not resuscitate, use of a breathing tube, feeding tube, use of antibiotics, etc.) for people with cancer. This study answered the following question:

Research Question 2A: To what extent did the ABM intervention increase the likelihood of decision making and communication with respect to specific aspects of advance care planning

(i.e., do not resuscitate, use of a breathing tube, feeding tube, use of antibiotics, etc.) compared to the control group? The following analyses were performed:

- Chi-square was used to compare the experimental group to the control group for categorical data (e.g., race, sex, age, income, and education). The assumptions for the test statistic, chi-square, are independence of groups, adequate sample size per reported cell, similar and equal distributions between groups and variances, and categorical observations.
- Independent t-tests were used to compare the experimental group to the control group for continuous data (e.g., ACP decision making and ACP communication). The independent samples t-test was an appropriate test to evaluate the continuous, outcome variables. The assumptions for the independent samples t-test are expected to be met because the groups are independent of each other, homogenous, and the outcome variables are expected to be in a normal distribution. Homogeneity was measured and reported using Levine's test. When the t-test assumptions were not met due to abnormal distribution or heterogeneity, a Mann-Whitney U, non-parametric test, was used as the alternative statistical test.
- There were 22 items on the advance care planning survey, including decision making and communication for the following items: living will, ventilator, oxygen, feeding tube, IV fluids, blood transfusions, antibiotics, medical power of attorney, OOH/DNR, resuscitation, and calling 911. The survey was presented as a likelihood scale with likert options. The ACP Survey was scored from 1 to 6 with the largest number representing a completed task. The 11 scores for communication and the 11 scores for decision making were summed for each participant into two global scores.
- To control for Type 1 inflation due to multiple t-tests, a Bonferroni comparison was made by calculating an adjusted alpha level from the original alpha level divided by the number of analyses. The Bonferroni adjustment was planned for this study (Hinkle, Wiersma, & Jurs, 2003; Munro, 2002; Tabachnick & Fidell, 2007); however, if the descriptive statistics showed a non-normal distribution or violated other assumptions, then a non-parametric

adjustment was made. By using the global scores for communication and decision making, these two scores limited the adjustment ($\alpha/n = 0.10/2$ or 0.05) as compared to using multiple comparison tests for each item in the ACP survey ($\alpha/n = 0.10/22$ or 0.0045). Statistical significance focused on the certainty of proving the ABM intervention changed advance care planning using a control and a comparison, experimental group under strict statistical conditions. Clinical significance focused on the benefit gained by the intervention in context with causing harm to the participants.

For Research Question 2B: What were the remarks reported by participants on the postintervention evaluation interview and the observations of the research team associated with the utility and implementation of the ABM intervention?

- The postintervention evaluation interviews conducted with participants were summarized with percentages or frequencies (if appropriate). In addition, excerpts from the narrative responses were quoted as corroborating qualitative data. No formal qualitative analysis was undertaken in this study. The percentage of participants who agreed to participate in the interview was reported. For example the postintervention evaluation included: if the ABM intervention made it easier to communicate with others about their health-care decisions and if recalling memories was uncomfortable.
- The PI observation and implementation issues of the ABM intervention were important as well from a logistical perspective. These logistical issues included: the flow of the interventions, the receptivity of the grand tour opening question, the amount of prompting or encouragement to initiate the ABM intervention, and the overall sense of the intervention session. Quantitative data were reported, such as the mean length of the consent and ABM intervention (in minutes), the length of time to complete the ABM intervention, and the number of participant referrals for psychosocial or spiritual support.

Protection of Human Subjects

Regulatory Review and the Protection of Human Rights

The study was approved by two human subject review boards to establish regulatory compliance and ethical research while protecting the rights of humans. The University of Utah Institutional Review Board (IRB) was the initial body to review the proposal and approve it then Clinical Cancer Investigations Committee at the Huntsman Cancer Institute, and the Ethics Committee at Houston Hospice, responsible for reviewing all research protocols, reviewed and approved the study. The PI met with the chairperson of the Houston Hospice Ethics Committee to review the protection of human subjects and the submission requirements for this study. The PI provided an acceptable informed consent document to the University of Utah's IRB, which was later approved by the Houston Hospice's Ethics Committee. In addition to the study proposal, the PI submitted other documents to the IRB and Ethics Committee that included: advertising materials, education handouts, and informed consent.

Although health disparities exist in our society with the aged, elderly people with cancer at the EOL are especially vulnerable to health disparity and loss of self-determination. Patients who are geriatric and dying are considered a vulnerable population. There was no exclusion criteria based on ethnicity, race, education, or financial status, and the targeted population was people with cancer who are older than 55 years. Every effort was taken to preserve the participant's dignity, respect, and autonomy and be considerate of the participant's pain and fatigue level, symptom issues, and other burden that may exist during the session times. Eligibility criteria were reviewed by the PI before giving approval for the initial telephone contact made by the QA assistant. Before initiating the individualized ABM intervention, the participants were asked for their informed consent and were required to sign a consent form. If the participant was unable to sign the informed consent form, then the patient was re-evaluated based on the eligibility criteria. The PI answered all questions pertaining to the study to assure the participants' understanding. Before and during each session, the PI ensured that the participant was able to participate in the session. The PI could have elected to end or shorten the session if the participant exhibited symptom distress such as fatigue, pain, or shortness of breath, but this was

not necessary. The PI is an experienced advanced practice nurse and used her clinical judgment when such situations arose. The Ethics Committee at Houston Hospice provided oversight to participant safety and served the designated Data Safety Management Committee.

Confidentiality and Protected Health Information

All interactions containing participants' protected health information were kept strictly confidential and protected per the HIPAA policy and procedures at the University of Utah and at the Houston Hospice. Whenever possible, the study accrual number assigned to the participant was used to distinguish each participant while maintaining a confidential environment. A computerized database was created for this study, and any computer files containing protected health information were secured with passwords. Although limited access to these files was granted to the research nurse, the database was not used by her without the PI participation. All efforts to de-identify data were completed. No outside entity shared the computer database. A separate file for de-identification of the participant's study number was kept.

The study file contained the socio-demographic data and the individual results per data collection tools, the study materials given to the participant, and a signed informed consent. All files were locked in a secured, fireproof filing cabinet. Information from the interventional sessions was not disclosed to family, health-care provider, facility, or any other petitioner. This security protected the participant's intimate memories and maintained the trust that was built between the participant and PI.

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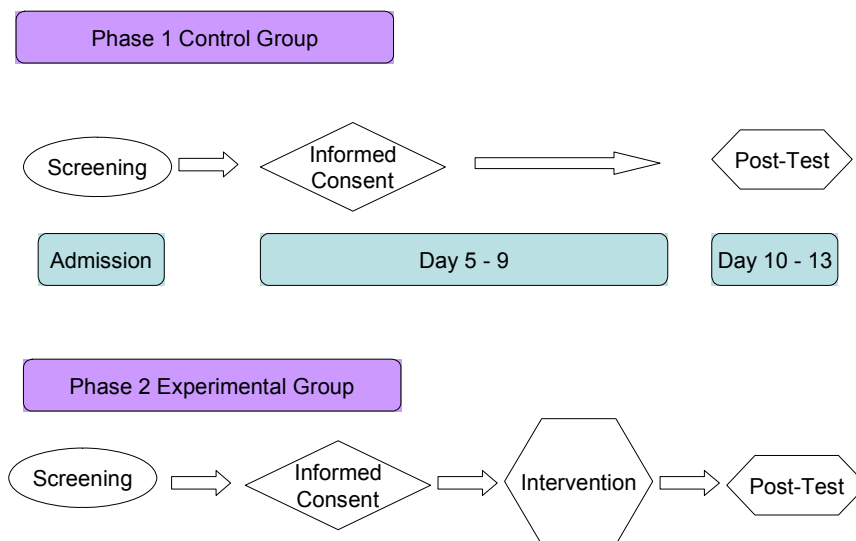


Figure 3.1. Study Design.

Table 3.1 Study Eligibility for Participants

Study criteria
Inclusion
<p>Participants will be eligible if they are:</p> <ol style="list-style-type: none"> 1. diagnosed with terminal cancer 2. actively receiving hospice home care 3. able to speak and read English 4. ≥ 55 years of age 5. cognitively intact per hospice nurse's clinical judgment 6. able to participate in study per Palliative Performance Score (PPS) $\geq 30\%$
Exclusion criteria
<p>Participants will not be eligible if they are:</p> <ol style="list-style-type: none"> 1. diagnosed with HIV, dementia, Alzheimer's disease, or clinically diagnosed depression 2. residing in an acute care facility or in the inpatient hospice facility 3. in possession of an executed living will or a medical power of attorney at time of consent

Table 3.2. Design Schema

Randomization	Intervention	Measurement Point 2
NR		O ₁
NR	X ₂	O ₂
Legend <ul style="list-style-type: none"> • No randomization procedure (NR) • An Autobiographical Memory (X₂) • Measurement points (O) 		

Table 3.3 Defined Dependent, Demographic, and Clinical Variables

Variables	Definitions
Dependent	<ol style="list-style-type: none"> 1. Decision making is defined as the cognitive process of reaching a decision. 2. Communication is defined as conveying information to another person either through written or verbal means. 3. Living Will is the legal document in the state of Texas that outlines a patient's health-care wishes. 4. Medical Power of Attorney is the legal document in the state of Texas that names a person for health-care decisions. 5. Out Of Hospital Do Not Resuscitate Order is the legal document in the state of Texas that defines the use of cardio-pulmonary resuscitation. 6. Full Code is defined as any means necessary to sustain life. 7. Mechanical Ventilation is the artificial means of breathing. 8. Oxygen is defined as an invisible gas administered through the use of a nasal cannula or a breathing mask. 9. Enteral tube is defined as a feeding tube to give nutrients. 10. Antibiotics are defined as medications to treat an infection. 11. Blood transfusion is defined as the giving of blood products. 12. IV fluids are defined as giving intravenous fluids. 13. Calling 911 is defined as contacting emergency service.
Demographic	<ol style="list-style-type: none"> 1. Age is defined as the number of years a person has lived. 2. Gender is defined as male or female. 3. Education is defined as the highest level of education completed. 4. Marital status is defined as the current marital status. 5. Children are defined as the number of children. 6. Primary caregiver is defined as the person responsible for care. 7. Insurance is defined as the principal payer of hospice bills. 8. Income is defined as the amount of yearly income. 9. Race/ethnicity is defined as origin of ancestry from birth. 10. Language(s) is defined as the primary spoken language. 11. Retired is defined as a person is not working for pay. 12. Occupation is defined as a person's job. 13. Zip code is defined as mail code of place of residence.
Clinical	<ol style="list-style-type: none"> 1. Date of diagnosis is defined as month/year of diagnosis. 2. Primary hospice diagnosis is the cancer type. 3. Years of cancer is defined as the years from diagnosis. 4. Co-morbidity is defined as a co-existing diagnosis. 5. PPS score is a predictive score for length of survival

Table 3.4 Data Collection Measurements

	Variables	Instruments	Method of Obtaining Measures
Antecedents	Demographic Variables Age Gender Education level Marital status Children Primary caregiver Insurance Income Race/Ethnicity Language(s) Occupation Zip code	Demographic Information	Electronic medical record (EMR) review
	Clinical Variables Date of diagnosis Primary hospice diagnosis Years of living with cancer Diagnosis (co-morbidity)	Clinical Resume	
	Screening Variables Length of survival	PPS score	
Outcomes	Advance Care Planning	Advance Care Planning Survey	Self-reports
	Intervention Evaluation	Postintervention Evaluation Interview	
Processes	Feasibility/Utility Data Reason for dropout Length of time in the hospice program Observation of PI and research team	Patient response	Self-report EMR review Research team
		Field notes	

CHAPTER 4

OVERCOMING RECRUITMENT BARRIERS AND ATTRITION TO CONDUCTING AN INTERVENTION STUDY WITH PEOPLE WITH CANCER RECENTLY ENROLLED IN HOSPICE

Cheryl L. Brohard, RN, PhD(c), AOCN^{®1,2}

Susan L. Beck, APRN, PhD, AOCN[®], FAAN²

Patricia H. Berry, RN, PhD, ACHPN, FAAN²

¹Houston Hospice

²University of Utah, College of Nursing

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Abstract

Significance

Recruitment and attrition are recognized barriers to intervention research among hospice populations. Conducting a feasibility study with a small group of participants enabled the researcher to identify these barriers and plan implementation strategies for a larger trial.

Study Design and Methods

The study design was an exploratory feasibility study using a quasi-experimental design. A convenience sample of 50 older people with terminal cancer recently enrolled into hospice with no advance directives was recruited for the control and experimental groups. People who were eligible, approached but refused to participate, approached but were not able to be enrolled, and those that were approached, enrolled, and completed the study were recorded and tracked.

Findings

There was no difference in demographic data between the consenting and nonconsenting groups in either the control or experimental groups. There was no attrition in this feasibility study, and a calculated ratio score of the number of people needed to be in the initial study pool to have one completed patient was 18:1, which are favorable results in comparison to other studies. These results were obtained by using a reliable prognostic tool and the electronic medical record for screening, simplifying the study procedures, and waiting a five-day window after admission to approach for study enrollment.

Discussion

Successful completion of intervention research with terminally ill cancer patients is vital to improving the quality of care at the end-of-life. This feasibility study provided a means of highlighting strategies to overcome the identified barriers to recruitment and attrition.

Introduction

Overcoming the barriers in hospice and palliative care research is a multifaceted challenge for the researcher conducting an intervention study. The complexity and variations of these barriers are abundant, serious in nature, and threaten the success of intervention research for the hospice and palliative care population. However, the discoveries of such research are vital to the emerging field of hospice and palliative care and to improving care for dying persons and their families. Finding effective strategies to minimize the barriers to conducting intervention research for hospice and palliative care will aid in bringing the research to full fruition.

Annually, there are 2.5 million deaths in the U.S., and people enrolled in hospice care account for half of those deaths (National Hospice and Palliative Care Organization, 2012). Even with the large volume of people in hospice care and end-of-life funded initiatives, the literature is scant for intervention research. With so few published articles on intervention studies conducted with this population, it is difficult to design foolproof methodological approaches that are proven and lead to successful completion (Cook, Finlay, & Butler-Keating, 2002). This report will summarize lessons from a feasibility study that was designed and implemented with a group of terminally ill people with cancer during their hospice trajectory.

Background and Significance

The review of literature will address hospice and palliative care patients as a vulnerable population as well as challenges and barriers (patient, organizational, and study-specific) to intervention research in the hospice setting.

Vulnerable Population

The challenges for conducting successful hospice and palliative care research are well-documented (Sherman, McSherry, Parkas, Ye, Calabrese, & Gatto, 2005). Initially, there were ethical questions of whether such research exploited a vulnerable population. This research was thought to be damaging, insensitive, and intrusive to people at the end-of-life (Walter & Read, 2011). Alternatively, to deny this vulnerable population the right to participate in a research study

would be to deny their autonomy and respect for humanity (Wohleber, McKittrick, & Davis, 2011). Palliative care patients volunteered for research studies mainly for altruistic reasons (Fairhall et al., 2011); they felt free to express themselves because they were dying and unrestrained (Terry, Olson, Ravenscroft, Wilss, & Boulton-Lewis, 2006). Participating in research enabled the patients to tell their story and help others before they die. It is through high-quality, rigorous, ethical research studies that the voices of this vulnerable population can be heard.

Challenges

Numerous challenges pertaining to recruitment and attrition faced end-of-life research studies (Goldberg, 2004; Goldberg, 2005): being labeled as terminal deterred patients from participating in end-of-life studies because they wished to avoid talking about or acknowledging their mortality; patients were too ill to participate in a study or complete the study; patients were overwhelmed and refused to participate; and the family served as gatekeepers and denied researchers access. Goldberg (2005) and Kutner, Main, Westfall, and Pace, (2005) described an additional challenge of hospice research as the study criteria are too stringent or restrictive, preventing enrollment of possible participants. In particular, identifying cancer patients who meet the criteria of being at the “end-of-life” has been difficult due to the inability to predict prognosis. Shah and others (2006) identified the incongruence between the patients’ and the physicians’ estimated life expectancy, therefore making it difficult to identify cancer patients who are dying. In the clinical world, this difficulty may result in delayed referrals to hospice. In the research world, it makes it challenging to identify potential research participants.

Barriers

A taxonomy of barriers as proposed by Hagen, Wu, and Stiles (2010) included a categorization of the barriers of conducting a clinical trial with palliative care populations; the taxonomy included barriers as patient-related, organizational, logistical, and study specific. Patient-related barriers were identified as patient illness, high rates of comorbid conditions, and high attrition rates. Gatekeeping and the organization’s infrastructure to support research were

identified as organizational barriers. Logistical challenges were cited as time and money. Study-specific barriers included low prevalence of the problem, study design such as a randomized clinical trial that may not be appropriate or acceptable for dying patients, restrictive eligibility criteria, multiple data collection points, and trial design complexity such as too much paperwork or response burden for sick people.

Patient-Related Barriers of Illness, Co-Morbidities, Prognosis, and Attrition

Patients enrolled in hospice are recognized as having a life-limited prognosis. Progression of cancer, preexisting conditions, and end-of-life symptoms are factors in the patient being too ill to enroll in an intervention study. Physical symptoms derive from the type and stage of the cancer and the existing co-morbid conditions. Physical symptoms cited as common at the end-of-life are pain, dyspnea, congestion, edema, ascites, nausea, and vomiting (Stark, Tofthagen, Visovsky, & McMillian, 2012). Among the possible psychological symptoms at the end-of-life are anxiety, depression, confusion, diminished responsiveness, hallucinations, and delirium (Stark et al., 2012). Geriatric-oncology patients have an average of five or more co-morbid conditions (Yates, 2008). These co-morbid conditions can negatively influence the patient's physical and psychological well-being at the end-of-life.

Overestimation of prognosis (Shah et al., 2006) and difficulty having the EOL conversation (Arora, 2003; Hickey, 2005; Thorne, 2005) impact the low volume of hospice referrals and the short length of stays in hospice. Short length of survival for patients with cancer in hospice is common. McCarthy, Burns, Davis, and Phillips (2003) conducted a retrospective analysis of a large number of patients in the Tumor Registry Database ($n = 62,117$). They found 27% of patients with lung cancer and 20% of patients with colorectal cancer received hospice care, and 20% of those entered hospice within a week of their death. Wohleber and others (2011) found that 51% of patients died in the first month after being referred to hospice.

The large majority of patients with cancer are entering hospice care with days to weeks to live. The deterioration of a patient's physical and mental faculties is inevitable, but the timing of when it will happen is unpredictable. Farnon and Hofmann (1997) found that 35% of patients ($n =$

100) died within seven days of admission to hospice, and the majority of these patients were hospitalized (58%) and diagnosed with cancer (61%). Short hospice survivals or short length of stays prohibit study designs that are longitudinal and involve multiple data collection points. Conversely to the short length of stay, barriers are patients who were not interested in enrolling in a palliative care study because they had other priorities like spending time with family, having a previous bad experience with research, and experiencing emotional distress associated with learning about their terminal diagnosis (Phipps et al., 2005).

Attrition rates are high for people who enroll in a hospice research study (McMillan & Weitzner, 2003; McMillan & Small, 2002). To avoid the high attrition rates of patients, some researchers redirected their efforts on intervention research to caregivers (Northouse, Katapodi, Song, Zhang, & Mood, 2010). Caregiver studies proved to be difficult to complete as well. Caregiver strain and burden can be overwhelming in dealing with the patient's expected symptoms during the end-of-life phase (Honea et al., 2009). Lack of knowledge or commitment to provide patient care, financial concerns, socio-cultural issues, and psychological stress contribute to the caregiver's strain. Caregiver attrition (21%) in a problem-solving intervention study for negative life events and daily challenges was attributed to the patient's death or a deteriorating physical and psychological condition (Demiris et al., 2010). The intensity of the patient's deteriorating condition and the amount of caregiver strain have been cited as the primary reasons for patient's exclusion for participation in a research study. Family members and caregivers are often the gatekeepers to patient access.

Organizational Barriers of Gatekeepers

Access to patients may also be blocked by other protectors. The protector may be the hospice agency, the individual hospice's Ethics Committee, the hospice interdisciplinary team, or other members of the health-care team. The goal of hospice is to provide compassionate care at the end-of-life, and members of the Ethics Committee may find that approving a research study is against the mission of hospice. In response to this, the National Hospice and Palliative Care Organization (NHPCO) (Casarett et al., 2001) and the American Academy of Hospice and

Palliative Medicine (2007) issued a position statement that encouraged hospice providers to facilitate research studies by making open access to patients available for researchers, citing that patients have a right to choose whether they participate in a research study.

Study-Specific Barriers

For those patients who do agree to participate in an intervention study, it is important to reduce the complexity of the study design and consent process. Hagen et al. (2010) advocated for a reduction of patient burden with the informed consent documents by simplifying the wording, eliminating extraneous information, and altering the delivery of it (e.g., verbal instead of written). Limiting the number of data collection points and streamlining data collection procedures also will minimize patient burden.

Eligibility Criteria

Stringent inclusion and exclusion criteria may eliminate participants. Maximizing the volume of eligible patients through less restrictive eligibility criteria provides a large pool of potential participants for enrollment. Hagen and others (2010) defined the number needed to assess (NNA) as the ratio of the number of patients needed to be in the initial study pool to have one completed patient and used this evaluation measurement for two intervention trials. For a prospective open-label drug trial, it took 250 NNAs for every one patient completing the study. For a randomized clinical trial, it took 83 NNAs for every one patient completing the study. For researchers conducting intervention research, the NNA is important. The NNA ratio should be calculated after the completion of the feasibility study to determine if the partnering hospice has enough volume for accrual and for how long the study will take for completion.

Significance

The complexity of planning, funding, and completing an intervention study should not overshadow the importance of conducting this type of study. The findings of hospice and palliative care intervention research studies are needed to provide an evidence base for end-of-

life care including solutions to help caregivers deal with the strain of caring for the dying patient and to provide springboard for death and dying policy.

Purpose

A feasibility study can be helpful during the planning stages of a randomized clinical trial. Hagen, Biondo, Brasher, and Stiles (2011) suggested a feasibility study be undertaken to evaluate the potential success of the planned overall project and identify the multi-dimensional challenges of intervention research with people enrolled in hospice. Once the challenges of recruitment, accrual, enrollment, implementation of the intervention, and attrition are identified, then pragmatic strategies can be offered to increase the likelihood of success in a larger trial. The purpose of this article is to describe the lessons and application of successful recruitment and retention strategies from a feasibility study of an autobiographical intervention for people with terminal cancer enrolled in hospice.

Aim

The aim of this study was to test the feasibility of recruiting and retaining hospice patients to a pilot study of an intervention. We describe the results of the screening process and number screened in order to find eligible participants. We also compare the number, percent, and characteristics of eligible participants who consented and participated in the study to eligible and nonconsenting patients for both the control and experimental groups. Rates of attrition are also reported.

Design

The study used a quasi-experimental design to evaluate the efficacy of an autobiographical intervention on advanced directives. Recruitment and accrual occurred over a 12-month period in two phases with two independent groups of participants (refer to Figure 4.1, Study Design). Both phases consisted of Screening, Enrollment, Consent, and Evaluation; in addition, Phase 2 participants received the autobiographical intervention. The study was

approved by the Clinical Cancer Investigations Committee at the Huntsman Cancer Institute, University of Utah's Institutional Review Board, and the hospice's Ethics Committee.

Setting

This study was conducted in a large hospice in Southwest United States that served 10 counties with the largest volume of people referred from acute care hospitals and several hospital-based cancer centers. It was expected that the participants would be diverse in age, race, and diagnosis based on the available population in this geographical location. The hospice was equipped with an electronic medical record (EMR) that was used by the clinicians from the time of referral until the completion of the bereavement period.

Criteria for Study Participation

Eligibility criteria were carefully determined to guide the recruitment for the study. Excluded from the study were potential participants with HIV, dementia, or clinical depression, and those with an advance directive (living will or medical power of attorney) as this was the outcome of interest. The inclusion criteria included being terminally ill with cancer, age 55 or older, able to read and speak English, and cognitively intact and having a minimal Palliative Performance Scale score of 30% or greater.

The Palliative Performance Scale (PPS) is a valid and reliable prognostic tool shown to be significantly associated with length of survival of terminally ill patients with cancer and severity of illness (Downing et al., 2007). The scale is divided into 11 categories, measured in 10% decremental levels starting with independence (100%) down to death (0%) and evaluates five physical and functional parameters: the degree of ambulation, the ability to do activities and extent of disease, the ability to do self-care, the intake of nutrients, and the level of consciousness (Victoria Hospice Society, 2003). The total PPS score is an aggregate of all the parameters (Victoria Hospice Society, 2006). For this study, the initial admission PPS score was recorded in the EMR by the hospice nurse. In previous research, the PPS scores (i.e., 30%, 40%, and 50%) on admission were found to be valid and statistically significant ($p < 0.01$) for

estimating the length of survival (Head et al., 2005). Brumley and others (2007) excluded 50% of patients in their study by using a PPS cutoff score of 70% or less, and of the 310 patients randomized for the study, only eight patients died during the study.

Procedures

Written procedures and checklists associated with screening, enrollment, consent, intervention, and evaluation helped to ensure all activities were accomplished. Three members of the research team performed study duties. The PI screened all new admissions to hospice for study inclusion using the EMR; demographic and clinical information were accessible to the PI for recruitment purposes. The PI negotiated with the clinical leaders of the hospice to designate one person within the organization to assist with recruitment; the hospice's Quality Assurance (QA) assistant was selected. The QA assistant introduced the study to potential participants by phone. The PI then consented all interested participants in their home and facilitated the intervention during Phase 2. A research nurse performed the evaluation duties, which included telephonic administration of the advance directive survey and, during Phase 2, a postintervention evaluation interview.

Both the QA assistant and the research nurse were provided a study proposal and attended an educational session with the PI regarding the aims, criteria, procedures, forms, and recording of their interactions with the patients. The QA assistant was monitored by the PI on the initial patient who was telephoned and continued to be monitored sporadically during the accrual period. The research nurse had over five years of hospice experience and previous cancer clinical trial experience that included administration of surveys and interviews.

The hospice required that all new patients be seen by a registered nurse, social worker, and chaplain within 5 days after admission, and if needed, a hospice aide and medical director also visited. Thus, the first 5 days were a very tiring and demanding time for the patient and primary caregiver. Based on these logistics and the study design, timing of the patient contact was extremely important to avoid this busy period. To avoid overwhelming the potential participant and caregiver and risking a refusal due to fatigue, the PI conducted an initial screening

of eligibility on admission and monitored the candidate for uncontrolled symptoms and PPS score changes during the 5-day period using the EMR. The PI notified the QA assistant by email when to contact the potential participant to discuss interest in the study. One final screening in the EMR was conducted immediately prior to the QA assistant telephoning the potential participant. We documented reasons that some potential participants elected not to enroll in the study. The QA assistant would email the list back to the PI with the potential participant's enrollment decision.

The PI telephoned the potential participant for an appointment date. Between the time of the phone call and the appointment, the PI monitored the EMR for any issues that would prohibit the potential participant from participation. On the morning of the appointment, the PI confirmed with the potential participant that the time was still convenient for the home visit. If the potential participant was not available to talk, then the PI introduced herself to the caregiver and the purpose of the visit. Sometimes caregivers would report that overnight the potential participant had developed uncontrolled symptoms or psychological decline and would no longer be able to participate in the study. In the situation when the PI went on the home visit and potential participants were not eligible for the study due to a functional decline; for example, the PI shared with the potential participant or caregiver that the patient no longer met criteria, and if appropriate, the PI offered assistance to call the hospice team or offered the agency's resources for end-of-life management. The PI graciously thanked the potential participant for his or her interest in the study.

The enrollment visit was to verify eligibility, confirm demographic and clinical information, and obtain written consent. The consent document provided a detailed explanation of the study, purpose, procedures, time commitment, risk and benefits, and study requirements and was reviewed with each potential participant. The consent form was written at an eighth-grade reading level to simplify the language for the participant. Approved by the regulatory bodies, a one-page flyer was provided to the participant as a quick summary of the study.

During the consent, the PI streamlined the collection of demographics and clinical information by confirming the data, such as date of birth, marital status, and insurance, rather

than asking the participant for the data. The PI relied on the admission nurse and social worker's documentation of the existence of advance directives in the EMR. Another consideration that we subsequently eliminated was to request the participant share a copy of the advance directive as part of the exclusion criteria; this idea was determined to be too restrictive, labor and time intensive, and potentially adversarial if the document could not be found. Participants' self-report was thus considered adequate for exclusion.

After consent and signatures were obtained in Phase 1, the participant was given a copy of the informed consent document and made arrangements to complete the evaluation with the research nurse. During Phase 2, the intervention was completed during the first and only visit to the participant's home immediately following the consent process. The intervention was designed for 60-90 minutes in order to keep participant fatigue and visit burden to a minimum.

The PI concluded the consent visit by contacting the research nurse who conducted the evaluation over the telephone. This evaluation was completed at a convenient time for the participant within four days of consent visit. Once the evaluation was completed, the PI sent a thank you letter and a monetary gift of \$10 to the participant. This monetary gift was approved by the IRB and the agency's Ethics Committee.

Data Analysis

Data were managed through three software programs. The initial screening data were collected in a Microsoft Excel document as this included all new patients enrolled into the hospice program. For potential participants that were approached for enrollment, the PI entered data into REDCap, a secure, web-based application for building and managing online databases, used at The University of Utah, College of Nursing (Harris et al., 2009). Data from the REDCap database were exported to SPSS version 20.0 for final statistical analysis.

The PI developed several reports in the REDCap system to check for missing data, errors in data entry, accuracy, and completeness. The data were exported to SPSS and checked again for data integrity using frequencies; box plots, which identified outliers; and histograms, which identified distributions and volumes. Descriptive statistics detail the demographic and

clinical characteristics of the consenting participants and nonconsenting potential participants in the control and intervention phases. An Enrollment Algorithm illustrating recruitment, enrollment, and attrition was created to describe the number potential participants screened, eligible, not eligible, and those potential participants in the two phases that consented and completed the study (refer to Figure 4.2).

Findings

All people electing hospice were screened using the eligibility criteria as depicted in the CONSORT diagram (refer to Figure 4.2). From the 1,807 people who were screened for the study from January to December 2011, 50 participants were successfully accrued and completed the study. Of the 1,807 patients who were eligible for enrollment, 1,757 patients were excluded and the majority of those patients (91%, $n=1,642$) did not meet study criteria (refer to Figure 4.3).

Detailed data of those patients excluded from the study found that more than half (56%) of the 1,642 people did not have cancer ($n = 913$), leaving 729 diagnosed with cancer that did not meet the study criteria. Approximately half of the 729 people were receiving inpatient hospice care, which means they had uncontrolled symptoms, transitional symptoms, or were actively dying and had a corresponding PPS score of 30% or lower. In addition, these patients were often not cognitively intact or capable of participating in the consenting process. Of the 345 people who were diagnosed with cancer and received home hospice, the two most prominent reasons for ineligibility were uncontrolled physical and psychological symptoms based on the inclusion criteria of the Palliative Performance Scale.

Six percent of all patients were the nonconsenters who refused to participate ($n=87$) or were found to be ineligible due to physical or cognitive decline ($n=28$). They developed uncontrolled physical and psychological symptoms similar to those who were ineligible. Some of the nonconsenters refused to participate in the study. Refusal reasons were categorized as patient-related and found patients that were approached voiced no interest or refused the study, the QA assistant or PI was not able to contact the patient, the patient cited too much going on, and the caregiver said he or she was overwhelmed. Comparisons of the demographic and

clinical characteristics of the consenters and nonconsenters in the control group and the experimental group are displayed in Table 4.1.

There were 155 patients followed after the study ended and until death or revocation. Ten patients were lost to follow-up because they revoked hospice care to seek cancer treatment (Table 4.2). There was no difference between the consenters and nonconsenters in the control and experimental groups or when compared to all possible participants for the number of days from approach to death.

Consenters and nonconsenters in the control and experimental groups were statistically equivalent. Using a chi-square analysis, there were no gender, marital status, ethnicity or race, or insurance differences between the groups (Table 4.1). A chi-square analysis was performed and a statistically significant relationship between consenters and nonconsenters in the control and experimental groups and the PPS score was found $X^2 (15, N=165) = 30.99, p<.05$; however there was an insufficient count in 14 cells that violated the chi-square assumptions (Table 4.1). The PPS scores of 60 - 80% were collapsed into one variable which was renamed "60%+". Even with recoding, chi-square analysis showed 25% of the cells had counts of less than 5. The Fisher's Exact test was used to resolve the issue and showed a value of 13.4 ($p = .13$, two tailed, 4x4) some evidence of a trending relationship between PPS score and groups. The standardized residual of 2.3 with the nonconsenters in the experimental group showed an over representation of 30% PPS scores with 20 observations as compared to the 12 that were expected. The standardized residuals for the consenting control group (-.8), nonconsenters in the experimental group (-1.0), and consenters in the experimental group (-1.3) indicated that there were slightly less observations than expected. It appears that potential participants in the nonconsenters experimental group) with a 30%PPS were less likely to enter the study.

The postintervention evaluation included the answering of 24 questions of a likert-scale designed survey and an option for 11 additional questions specifically about the intervention for the experimental group. All participants (100%) participated in the survey; however, 48% of the consenters ($n=12$) agreed to the postintervention evaluation of the ABM intervention. Of those who did not participate, fatigue was the cited as the reason.

For this study, 18 was the calculated ratio score of NNA, the number of people needed to be in the initial study pool to have one completed patient. Figure 4.4 depicted the NNA pyramid which showed the total pool of potential eligible study candidates ($n = 894$). These candidates were screened for enrollment and 165 people were determined to be eligible. These candidates received detailed screening and were approached for enrollment. Fifty patients gave verbal consent over the telephone. All 50 candidates that signed consent forms completed the study; no attrition was reported in either control or experimental group.

The postintervention evaluation included the answering of 24 questions of a Likert-scale designed survey and an option for 11 additional questions specifically about the intervention for the experimental group. All participants (100%) participated in the survey; however, 48% of the consenters ($n = 12$) agreed to the postintervention evaluation of the ABM intervention. Of those who did not participate, fatigue was the cited as the reason.

Discussion

Successful completion of hospice intervention research can be achieved with resolution of barriers and challenges specific to this specialty research area. Enrollment into this study had its challenges. Improving earlier and ongoing identification of patient-related barriers such as physical and psychological functioning and study-specific design such as appropriate eligibility criteria, two data collection points, and simplification and reduction of paperwork ultimately resulted in a pilot study with no attrition and less people needed in the initial study pool to complete one patient in the study as compared to other studies. Despite the success of this intervention study, the 12-month patient accrual period reflects the experience of other hospice researchers (McMillan & Weitzner, 2003; Wohleber et al., 2011) and could be shortened with a larger volume of hospice patients meeting the eligibility criteria.

Another possible barrier to enrollment was the limitation of only having one invitation to participate in the study. The research team decided that a second invitation coming from the QA assistant or the RN case manager maybe viewed as patient coercion; a second invitation had not been included in the IRB proposal or as part of the study schematic. The QA assistant reported

that most potential participants that refused the invitation did so in a few words. Researchers may improve enrollment in an end-of-life study if a second invitation was extended to potential participant's reporting fatigue at the suitable interval postinitial invitation. A suitable interval would depend on the potential participant's physical findings and symptom control. Fatigue was also reported during the evaluation of the intervention and must be recognized and planned for in the methodology design by researchers as a barrier to completing hospice research. In an effort to improve the percentage of consenters participating in the evaluation of the intervention, researchers could conduct the evaluation in person on a separate day or incorporate questions at the end of the intervention.

It is critical to the success of a feasibility study that the PI understands the organizational structure and clinical operations in order to utilize the best strategies for accrual. Partnering with a hospice or hospices with a study pool of patients sufficient to accrue patients in the allotted time frame is an essential strategy. Asking for the assistance of the hospice employees for screening and enrollment support is an excellent strategy to engage the staff in research. Equally important is asking for support from the agency's leadership and understanding expectations in the agency's approval process. For future research studies, it is important to build a relationship with the hospice on a long-term basis. The training and education of the research team are critical to provide consistency between the stages of the study design, the approved IRB protocol, and the implementation of the study. Check and balances built into the program provide a means to measure the consistency of the research team and the proposed processes.

NHPCO (2010) reported 56% of hospice patients are female, about 80% are Caucasian, and 84% have Medicare insurance; eligible potential participants in this study showed 51% were female, 70% were Caucasian, and 74% had Medicare insurance. Minority participants represented 30% of the sample, which aligned with the results reported by Goodman (2011) with 70% of hospice participants as Caucasian. Our demographic characteristics are congruent with the ethnical diversity of the region.

Patients with terminal cancer accounted for 47% of the hospice enrollment during this period. Short length of survival was a common experience for this hospice. Near-death referrals

coupled with uncontrolled symptoms, age, and the ability to speak English were primary reasons for people with cancer being excluded from the study ($n = 729$, 38% of total screened). Of the 165 people with cancer who met criteria and were recruited, 41% agreed to participate. The results of this analysis showed that inequality of the consenters and nonconsenters for the PPS and demonstrated the need and utility of the PPS as a screening tool for hospice research. The criteria were vital to the study aims as other hospice and palliative care researchers have reported; too restrictive criteria limit potential participants (Goldberg, 2005). The criteria related to the hospice setting (i.e., home hospice or inpatient hospice) could be eliminated because the location of hospice care is not as important as the patient's functional status. Using a telephonic evaluation necessitated the need for the participant to hear and converse which could be too restrictive for patients with major sensory deficits such as deafness or muteness from a laryngectomy. Although 41% agreed to participate, many had declined at the time of the consent process. However, a total of 28 participants, 15 and 13 participants in the control and experimental groups, respectively, were approached, agreed to participate but were not able to consent mainly because of their decline in physical and psychological functioning. Making use of the EMR enabled the PI access to the most current health-care information at the patient level to ensure eligibility criteria were met before the recruitment call was made. Access to this information spared the caregiver of an unnecessary telephone call regarding the study when the patient no longer met criteria.

The 18 NNA results for this study compared to the Hagen and others' (2010) results of 83 NNA to 250 NNA for two intervention studies indicated our study had a better rate of conversion (Figure 4.4) from consenting to completion with the approximate same initial study pool. The expertise of the research team, with hospice care and prior research experience, contributed to the reported attrition rate as well as its adherence to the windows of time set up in the study design (see Figure 4.1). The rigorous procedural steps, the practical and minimalistic eligibility criteria, and checklists contributed significantly to the low NNA ratio.

The combination of access to patient information using the agency's EMR and using the PPS scale to predict prognosis were invaluable screening tools for this study. Both provided up-

to-date data on the potential participant's physical and psychological status. Simplifying the study procedures with an energy-conserving consent process and waiting a 5 day window after the hospice team had completed its initial comprehensive assessment were effective strategies on approaching previously identified study accrual barriers.

Limitations

The study was limited by a convenience sample of participants from one hospice agency. The final sample was small as it was originally proposed in the feasibility study. Although the sample was small, it was a sufficient number to test our study design while having relative success in our recruitment efforts and no reported attrition from the consenting participants. No new barriers or challenges were discovered that had not been previously reported by hospice researchers. There was no alternative approach to compare this study as the intervention and procedures were unique and specific to the population of interest. The nature of the intervention or the subject matter of the study may have deterred potential participants that were not interested in the study; however, they did not elaborate on their response to the QA assistant. Participants were terminally ill with cancer, which limited the generalization of this feasibility study to hospice and palliative care cancer patients that were cognizant of their terminal status. The procedures and strategies implemented for this study may be unique to the hospice and its population. No modifications or alterations were made in the screening and data collection; one implementation procedure was abandoned (tape recorder) due to technical failure.

It was a surprise to have no attrition. This study achieved an uncommon and unexpected result in hospice research of zero attrition by reducing the chance of dropout due to patient-related barriers of physical and psychological declines with the ongoing monitoring of the PPS score via the EMR. No attrition was attributed to minimizing the study-specific barriers with efficiency built into the study design and procedures such as the 5 day wait period. A third factor that may have impacted the low attrition was the motivation of the participant to participate in an encounter intervention study. The PI noted that participants expressed altruistic thoughts of

others who would die from cancer and their desire to help other people who would follow them on the end-of-life journey. Participants also commented about their eagerness to help with a doctoral dissertation because they knew someone who had completed a PhD. The last factor impacting no attrition was the one encounter intervention which is reasonable for the targeted study population and not dependent on long-term survival. The results of this feasibility study provide evidence that a randomized clinical trial would be successful using a similar study design with the elimination of the hospice location as part of the eligibility criteria and broaden the geographical location to areas outside of world-class hospitals focused on cure and restoration of health, which may provide longer length of hospice survival days for the patients with cancer.

Implications

The study implications for researchers related to screening and consenting participants to an intervention study include the use of the PPS score and the EMR to screen potential participants. Participants with a PPS score of 50% or greater had more time to plan for the end-of-life and were physically functional, cognitively sound, and easily engaged in the enrollment and intervention. PPS is a valuable tool when used as part of the eligibility criteria for enrollment into an intervention study.

On an annual basis, the nurses at this organization completed competency-based education and case studies establishing interrater reliability for the PPS, which established consistent assessment for all the potential participants considered for the study. With the data from past psychometric testing and the competency-based training, the PPS was viewed as a predictable tool for length of survival with terminally ill cancer patients. It can predict the course of the illness and death trajectory and serves an important tool for the nurse researcher conducting intervention research. Consistent training and ongoing evaluation of intra and inter-rater reliability is needed for clinicians or researchers to score the PPS.

Using the EMR, the most recent clinical assessment on the potential participant's cognitive intactness was obtained immediately before approaching the potential participant for enrollment permission. Uncontrolled symptoms triaged by the nurses during the night were

recorded in real-time. As displayed in the Enrollment Algorithm, many potential participants had a rapid decline during that 5 day window. Access to accurate and timely information about the patient condition was central to the research study. The potential participants and caregivers were spared the burden of deciding on a research study when the potential participant did not meet criteria; however, without the EMR, this burden would have been put upon the caregiver adding undue stress to the end-of-life period.

Summary

The preparation, procedural steps, and timing results of this feasibility study are promising from the perspective of screening potential participants with the eligibility criteria (i.e., PPS, cognitive status) and attrition. The PPS score was used in determining eligibility and was extremely helpful in avoiding the one of the biggest pitfalls of end-of-life research—attrition due to declining condition. Five of the 50 participants had a 30% PPS score on admission and were consented in the study. No fatigue was observed during the consent/intervention visit, but the visit was scheduled at the convenience of the participant, and the participants openly shared if mornings or afternoons were better for their lifestyle or condition. For intervention studies that last more than a few days or for longitudinal studies, a PPS score of 40% or greater is necessary and appropriate in the effort to ward off attrition. Working with a measurement tool with established validity, reliability, sensitivity, and utility is essential if the tool is used for eligibility criteria.

To be successful in completing end-of-life nursing intervention research studies, it takes strategic planning to address the common barriers that might be encountered. As researchers, we need to change the architecture of hospice research, accept the inherent limitations of the population, embrace the richness of the research and its findings, and alter our approach toward a patient-centered model. It is important to complete intervention research to improve the care of people at the end-of-life and provide the essential data for evidence-based quality hospice care.

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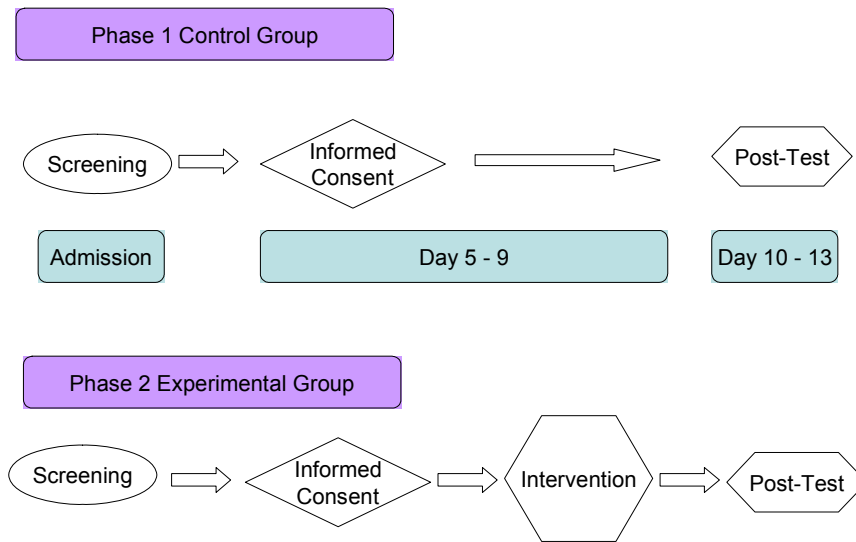


Figure 4.1. Study Design.

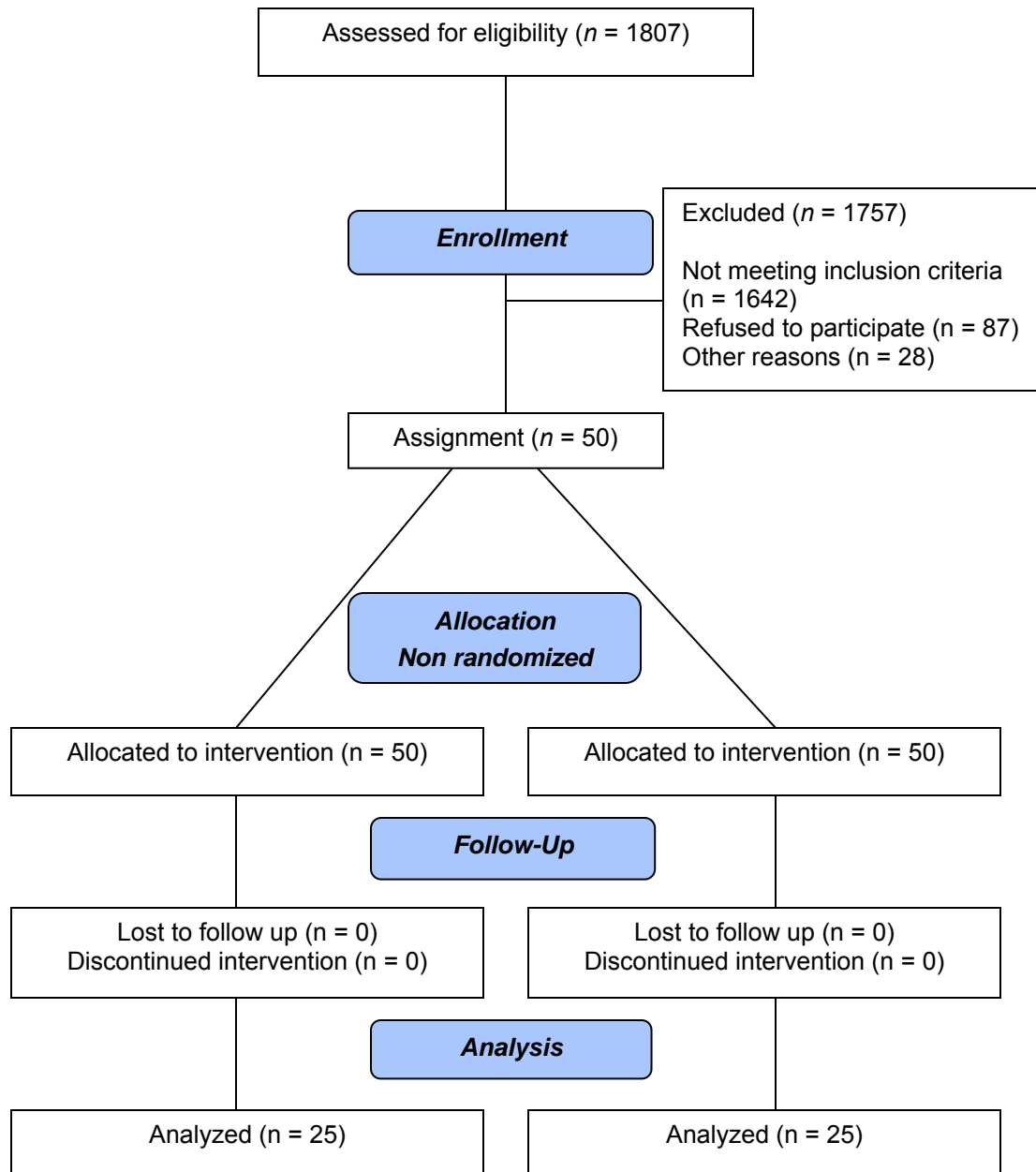


Figure 4.2. Enrollment Algorithm.

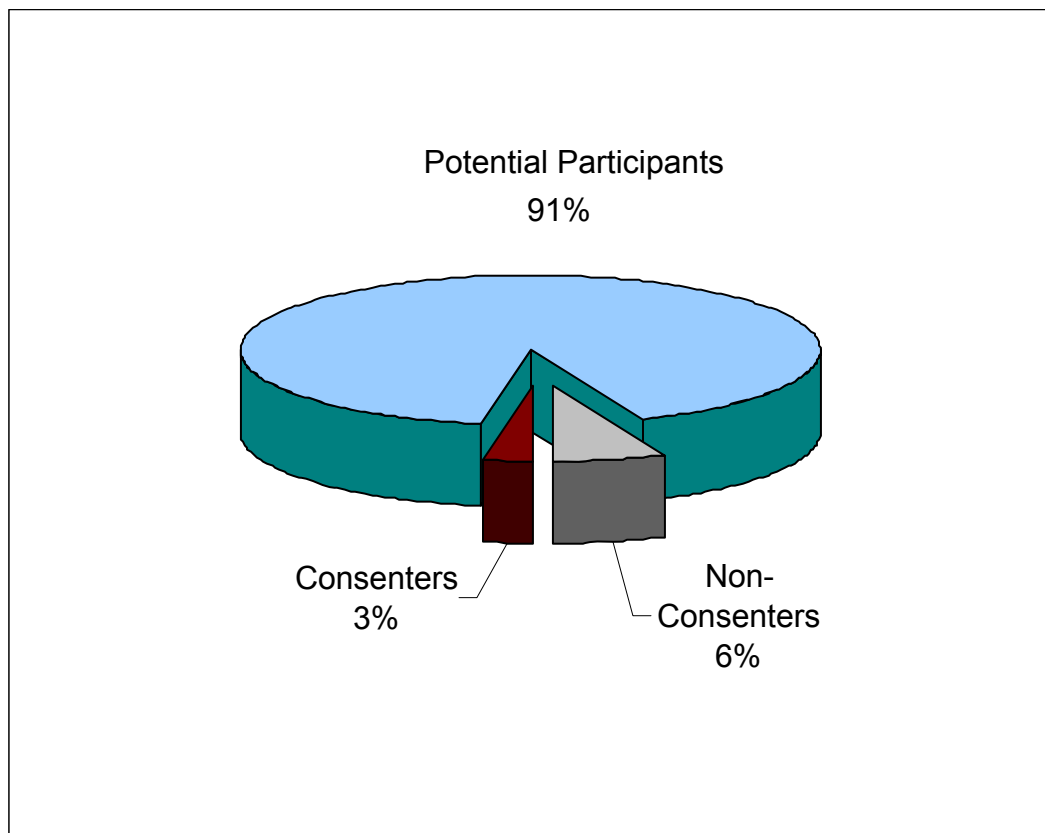


Figure 4.3. Distribution of Eligible Potential Participants.

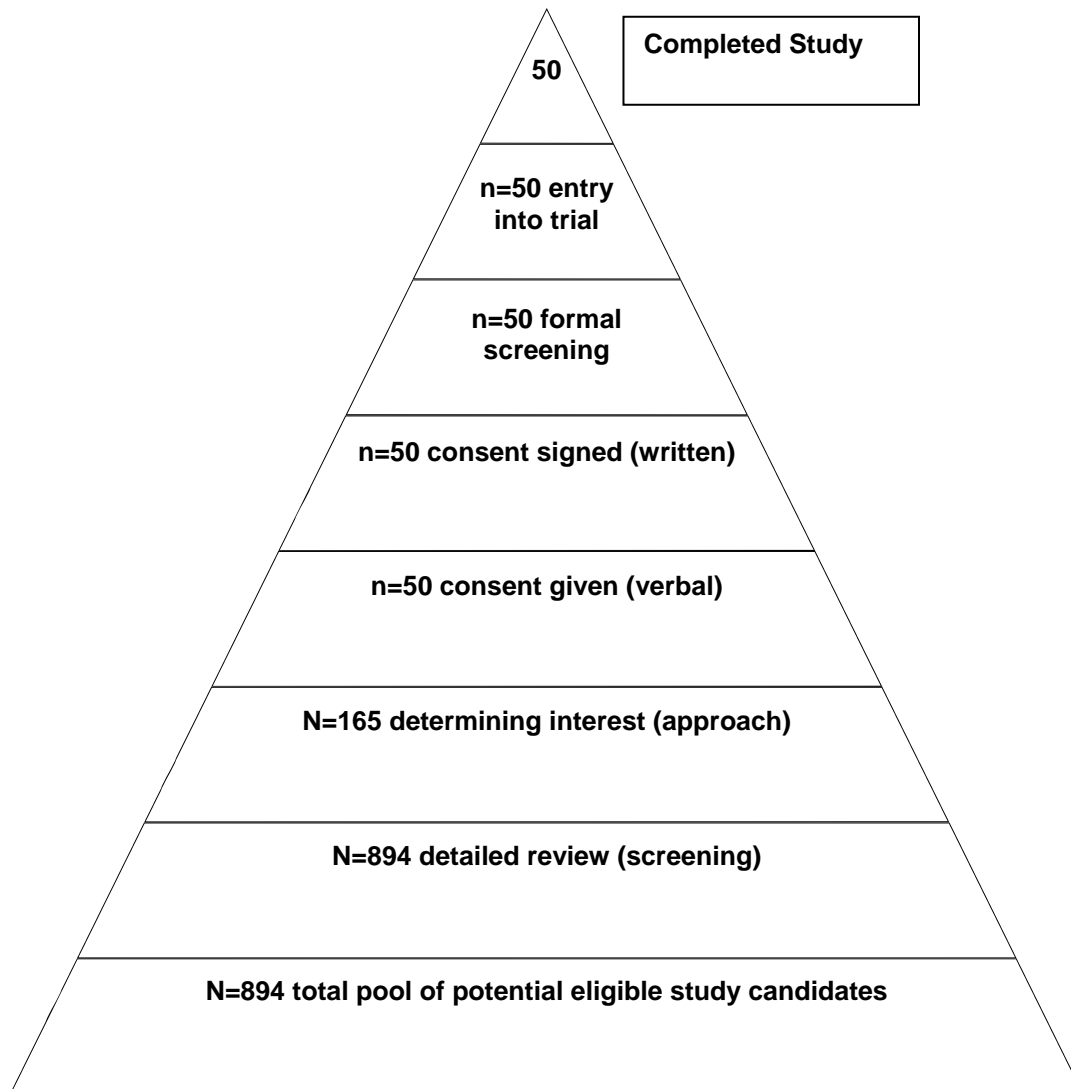


Figure 4.4 NNA Pyramid for Consenters in the Control and Experimental Groups published with permission from Dr. Hagen.

Table 4.1 Demographic and Clinical Characteristics of Consenters and Nonconsenters

Characteristic	Control Group n (%)		Experimental group n (%)		Chi sq
	Consenters (n = 25)	Non- consenters (n = 53)	Consenters (n = 25)	Nonconsen ters (n = 62)	
Gender					2.04
Male	15 (60%)	26 (49%)	13 (52%)	27 (44%)	
Female	10 (40%)	27 (51%)	12 (48%)	35 (56%)	
Ethnicity					.49
Caucasian	18 (72%)	40 (75%)	17 (68%)	45 (73%)	
All others	7 (28%)	13 (25%)	8 (32%)	17 (27%)	
Marital status					4.66
Married	16 (64%)	28 (53%)	11 (44%)	25 (40%)	
Not Married	9 (36%)	25 (47%)	14 (56%)	37 (60%)	
Insurance					.25
Medicare	19 (76%)	38 (74%)	19 (76%)	46 (74%)	
All others	6 (24%)	15 (26%)	6 (24%)	16 (26%)	
PPS (Initial)					30.99 ¹
Score 80%	2 (8.0%)	0 (0%)	0 (0%)	1 (2%)	
Score 70%	1 (4.0%)	1 (2%)	0 (0%)	3 (5%)	
Score 60%	0 (0%)	4 (8%)	6 (24%)	3 (5%)	
Score 50%	9 (36%)	23 (43%)	8 (32%)	17 (27%)	
Score 40%	10 (40%)	18 (34%)	9 (36%)	18 (29%)	
Score 30%	3 (12%)	7 (13%)	2 (8%)	20 (32%)	

¹Due to low cell counts, PPS scores of 60% and greater were collapsed and used in the Chi-square analysis

Table 4.2 Time from Approach to Death

	Number	Number of days from approach to death Mean (SD)	<i>t</i>	<i>df</i>	<i>p</i>
Eligible for Study					
Consenter	46	40.5 (44.8)	.61	153	.54
Nonconsenter	109	35.6 (48.1)			
DOD unknown	10				
Consenters					
Control	23	43.4 (53.2)	.42	44	.68
Experimental	23	37.7 (35.6)			
Nonconsenters					
Control	49	39.8 (61.0)	.86	107	.39
Experimental	60	31.9 (34.3)			

DOD = date of death

CHAPTER 5

INITIAL EFFICACY TESTING OF AN AUTOBIOGRAPHICAL MEMORY INTERVENTION ON ADVANCE CARE PLANNING FOR PEOPLE WITH TERMINAL CANCER

Cheryl L. Brohard, RN, PhD(c), AOCN^{®1,2}

Monisha Pasupathi, PhD²

Patricia H. Berry, RN, PhD, ACHPN, FAAN²

¹Houston Hospice

²University of Utah, College of Nursing

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Abstract

Purpose/Objectives

To test the efficacy of a novel intervention to facilitate advance care planning.

Design/Research Approach

Exploratory, quasi-experimental pilot with two independent groups.

Setting

A large hospice located in the Southwest US.

Sample/Participants

A convenience sample of 50 participants with terminal cancer enrolled in hospice.

Methods/Methodologic Approach

An autobiographical memory intervention used the participants' past experience with cancer and end-of-life for the purpose of directing advance care planning.

Main Research Variables

Two domains of advance care planning, decision-making and communication, were measured in relation to 11 variables (e.g., resuscitation, tube feeding, and oxygen).

Findings

The ABM intervention was non-threatening, short in duration, and easily completed with participants as they recalled without hesitation specific personal memories of family and friends that had died and their advance care plans. The Mann-Whitney non-parametric tests revealed that participants in the experimental group had a higher average rank ($p < .01$) than the participants in the control group for communicating the decision about antibiotics and a trend toward significance for five other advance care planning variables.

Conclusions

Findings showed that directive autobiographical memories may be effective in influencing the decision making and communication of ACP for terminally ill participants with cancer.

Implications for Nursing/Interpretation: The current level of understanding about utilizing the ABM intervention is limited; validation in a larger randomized clinical trial is recommended.

Introduction

The majority of people with cancer, including those in hospice care, will die without an advance directive or even a discussion about preferences for care. The process of obtaining information on life-sustaining treatments, deciding on the treatment, sharing the decision with others, and completing an advance directive for the end-of-life period is called advance care planning (National Hospice & Palliative Care Organization [NHPCO], 2012). For over two decades, research has provided a limited understanding of end-of-life and advance care planning (ACP) despite the efforts of several nationally funded initiatives. The need to find a successful intervention to facilitate end-of-life discussions and decision making is paramount with today's death statistics (NHPCO, 2012) and as the population ages. Approximately 77% of all cancers are diagnosed in people 55 years and older (American Cancer Society, 2012). To date, there is no effective evidence-based educational intervention to facilitate the decision making or communication with completion of ACP. Assuming that people are educated about ACP, then finding an alternative solution for the lack of ACP must be considered. An autobiographical memory (ABM) approach that includes problem solving combined with the natural processes of reconciliation of one's life when death is unavoidable is one potential solution. Recent research findings using autobiographical memories show promise as a means of influencing and directing future decisions and communications for individuals in domains other than end-of-life/ACP (Pillemer, 2003). The purpose of this exploratory study was to test the efficacy of a novel ABM intervention to promote ACP in older people with cancer on hospice care.

Literature Review

Advance Care Planning (ACP)

According to the NHPCO (2012), less than 35% of people have some form of advance directive. Legally binding advance directives vary by name across the U. S. and are grouped into two categories: the living will, also known as a health-care directive or a medical declaration outlining permissible medical interventions, and the medical power of attorney, also called a health-care proxy naming a surrogate decision maker. Kierner, Hladschik-Kermer, Gartner, and Watzke (2009) reported that 85% of 108 people with terminal cancer did not make a decision about an advance directive, citing full trust in their physician (22%), optimism about their prognosis (15%), fear of under treatment (8%), needing more information (7%), deferring the decision to family member (7%), mistrusting their physician (4%), other reasons (5%), and giving “no comment” as the reasons for not making an AD (32%). However, having an advance directive (i.e., living will or a medical power of attorney) does not resolve the need for communication of these decisions (Scanlon, 2003).

Poor communication between patients and their health-care providers and the uncertainty of when to hold end-of-life discussions were identified as the major reasons for insufficient communication about ACP (Kass-Bartelmes et al., 2003). There was disagreement between patient and families about preferences at the end-of-life (Teno et al., 2004) and confusion over the one person to serve as the decision maker (Dizon, Gass, Bandera, Weitzen, & Clark, 2007). Researchers and end-of-life experts (Bloomer, Tan, & Lee, 2010) identified the need for better communication between the patient and family; they advised against depending on the written and legally executed advance directives to convey the patient’s wishes.

In a rather unique study design, Jones and others (2011) gave 77 participants, with a recurrent cancer diagnosis, a choice to be randomized or to select their preference of usual care or an ACP intervention. The ACP intervention consisted of an hour-long discussion with a mediator about the patient’s feelings of the future, communication with family and physicians, financial aspects, place of death, resuscitation wishes, and coping mechanisms. The usual care option was just that and had no intervention. ACP intervention was preferred 51% of the time

over the usual care option, but there was no difference in either arm regarding the number of reported discussions with friends and family about ACP (Jones et al., 2011). Linked with communication is the education component of the advance directive, which is required by law for health-care facilities caring for patients with federally funded health-care.

A systematic review showed a weak association between an educational intervention and the completion of an advance directive (Durbin, Fish, Bachman, & Smith, 2010). Analysis of 12 randomized and four non-randomized studies found the most common educational interventions were written materials such as the legal documents, brochures, and case scenarios, followed by verbal explanation (Durbin et al., 2010). Findings from this study showed inconclusive evidence that a single educational intervention, more than one educational intervention, or the combination of written and verbal explanation made a difference in completing an advance directive.

In an effort to impact the completion of an advance directive, specifically CPR, more recently video and computerized vignettes have been used with hospitalized patients with advanced cancer to discuss ACP, such as resuscitation or ventilator support. Eighty patients with advanced cancer viewed a 6 minute video on three vignettes of health-care preference depicting the prolonging of life in the intensive care unit with a simulation of CPR, the delivering of basic care with medications and oxygen in the hospital, and providing hospice comfort care with medications, oxygen, and assistance with care needs in the home (Vollandes et al., 2012). The researchers compared pre-post preference of care and reported no change between the ICU, basic medical care, and comfort care vignettes, and only 5% of patients changed their code status to do not resuscitate.

A group of researchers (Fried et al., 2011) in a search to increase participation in ACP conducted confirmatory analysis on three scales to measure the participation in ACP (decisional balance), the barriers of participation (religious and medical values/beliefs), and processes of change (five stages of change in the Transtheoretical Model (TTM)). The TTM stages of change are: precontemplation (no intention of changing), contemplation (thinking about the change), preparation (committing to change very soon), action (change is recent), and maintenance (change is made). This study was conducted with 304 participants for the purpose of showing an

association between the decisional balance and values/beliefs with the TTM stages of change. The researchers have proposed, but not yet studied, a tailored intervention approach to move the participant from one stage of the TTM to the next. To date, no approach to ACP other than education has been evaluated.

There is concurrence in the literature that patients need to be aware of their prognosis in order to make informed end-of-life decisions. Physicians are positioned to discuss cancer staging and prognosis; yet many avoid the topic of ACP (Barnes et al., 2011; Piers et al., 2011). Social workers provide valuable information and resources that are needed by the patient and family (Black, 2006). Oncology nurses are in key positions to have ACP discussions (Cohen & Nirenberg, 2011).

Autobiographical Memory (ABM)

The use of ABMs for problem solving and decision making is supported mainly in disciplines other than nursing. This literature review will provide an overview of pertinent research studies of ABM. ABMs are snapshots in time of unique and highly personal life experiences (Beike, 2007; Pillemer, 2003). Initially identified within the hierarchy of ABM were specific and general memories. Specific memories were theorized to be constructed with precise details, such as person, place, and time, and are positioned at the bottom of the hierarchy (Williams & Dritschel, 1992). At the top of the hierarchy are general memories. General memories fall into two types: categorical memories describe multiple occurrences of the same event, and extended memories describe events occurring over a period of time, which were also called lifetime periods by Conway and Bekerian (1987).

A unique function of ABMs is to recall a problem or situation that occurred in the past in order to apply what was learned to the present (or future) issue; this function is called directive (Bluck, 2003). Pillemer (2003) drew attention to the importance of the directive function of ABM with his work on traumatic memories. He said that the role of memory in human adaptation and problem solving of past experiences emphasized the evolutionary significance and practical

importance of directive function memories. The directive function of ABM is helpful from the standpoint of not repeating a mistake, changing one's life, or gaining insight into a situation.

One study provided the most compelling evidence that adaptation occurs after a death-related experience. The study was conducted with 52 hospice volunteers, age ranged from 20 to 86 years, comparing a novice group to a more experienced group (Bluck, Dirk, MacKay, & Hux, 2008). The research found more frequently remembered real-life experiences with death as a hospice volunteer were associated with lower levels of death anxiety and avoidance. Participants reported that death-related memories of an actual death experience were adaptive or directive in nature using the Thinking About Life Experiences (TALE) questionnaire (Bluck, Alea, Habermas, & Rubin, 2005). These types of experiences were reported as a landmark or momentous event (Pillemer, 2001) that altered the volunteers' lives from that point forward (Pillemer, 2001).

Using a detailed script with highly visual and familiar cue words and a single facilitator for the intervention were associated with improved retrieval of ABMs, and these ABMs provided a means to define and understand present problems and generate solutions (Goddard, Dritschel, & Burton, 1997). More recently, Williams and others (2006) used simple instructions and highly visual cue words to retrieve more specific memories ($p < .001$). Participants retrieved more specific memories following "be specific" instructions and for the highly visual cue words than for participants following "be general" instructions and when cues were abstract (William et al, 2006).

The ABM intervention drew from the participants' memories of the death of a family member or a close friend, which was considered a life-changing event on many levels and described as a turning point in one's life or as a momentous event that influenced all future events. It is theorized that the value of the event is so important that the life-altering event will be re-visited at intervals throughout our lifetime in memories or narratives that we tell to others (Pillemer, 2001).

In conclusion, ABM research demonstrates that a directive function serves as a means of adapting and problem solving. Directive function has not been used as an intervention at the end-of-life but has been researched as an adaptive function with hospice volunteers. This study

examined the efficacy of an ABM intervention for a directive function used with terminally ill people with cancer enrolled in hospice to influence ACP.

Aim and Research Questions

This pilot study examined the initial efficacy of a novel ABM intervention to promote ACP with older persons with terminally ill cancer recently enrolled into hospice care. The research questions included: to what extent does the ABM intervention increase the likelihood of decision making and likelihood of communicating with respect to specific aspects of ACP; what are the perceptions of the intervention by participants at study completion; and what are the observations of the research team associated with the utility and implementation of the ABM intervention?

Methods

Design

This was an exploratory, quasi-experimental pilot study to test the efficacy of a novel ABM intervention. This study was approved by the Clinical Cancer Investigations Committee at the Huntsman Cancer Center, the IRB at the University of Utah, and the Ethics Committee at the hospice.

There were two independent and sequential sample groups (i.e., control and experimental). Participants in Phase 1 (control group) consented and completed the ACP Survey from January – June 2011. Then, participants in Phase 2 consented, participated in the ABM intervention, and completed the ACP Survey by phone with the option of providing feedback on the intervention during a second period of July – December 2011. The principal investigator (PI) delivered the intervention and completed a postintervention researcher's observation survey with detailed field notes for each participant after the ABM intervention. Additionally, the PI tracked numerous procedural outcomes with respect to the study design, such as time spent on the consent procedure; time spent using ABM intervention, and other such process variables. The quasi-experimental approach was used to compare the measurements of the control group to the experimental group without randomization. We agreed with other researchers that identified

randomization as a patient burden for hospice and palliative care research and too complex for this group of patients with terminal cancer.

Sample

An a priori power analysis was used to calculate the sample size using G*Power Version 3.1.0 software program (Faul, Erdfelder, Lang, & Buchner, 2007). To estimate the sample needed to determine a difference between two independent groups, this study used an alpha of 0.10, power 0.80, and large effect size (Cohen's d) of 0.70. The a priori alpha level was set at 0.10, which was a reasonable level to determine if there was a large enough signal associated with the intervention as compared with the control group from this feasibility study to warrant further research (Bartlett, Kotrlik, & Higgins, 2001). Based on this analysis, a total of 50 participants were needed with 25 participants in each group. A convenience sample was recruited from a large hospice in the Southwest United States.

Setting

This hospice reported approximately 65% of the 2,000 admissions for 2009 were cancer related. The common diagnoses were lung cancer, a variety of GI cancers, and breast cancer. Approximately 85% were 55 years old or older. The average length of survival for people with a cancer diagnosis who were enrolled in routine home care at Houston Hospice was 50.1 days with a median length of survival was 16.5 days.

Eligibility Criteria

Eligibility criteria included: people recently enrolled in hospice with terminal cancer, receiving hospice care in the home, able to speak and read English, 55 years of age or older, cognitively intact as judged by the admission nurse, and a score of 30% or greater on the Palliative Performance Scale (PPS). Exclusion criteria included: people diagnosed with HIV, dementia, Alzheimer's disease, or clinical depression in addition to cancer, or people with an executed living will or a medical power of attorney (Texas legal documents) at the time of

consent. A living will and medical power of attorney are the legal documents for advance directives in the state of Texas, where the study was conducted.

Intervention

This study used ABM to facilitate ACP in patients with cancer at the end-of-life. The ABM intervention focused on the specific memories of a single episodic event, the lesson learned from that experience, and how these ABMs can help in the participant's present-day situation.

Episodic events are personal in nature with vivid sensory-perceptual-affective information and oriented to a person and to a time (Conway, 2001). For this study, the episodic event was constructed memories from the participants' perspective. The elicited episodic ABMs that were recalled were socially constructed from the participants' memories of the past experience.

Table 5.1 outlines the steps taken by the PI during the ABM intervention. There was an opening, middle, and closing of the ABM intervention, all of which were conducted, in addition to obtaining study consent at the first and only home visit.

Study Procedures

A structured and successful recruitment procedure was followed to screen and enroll participants in the study and is described in detail elsewhere (Brohard, see chapter 4). The study design included an initial screening of patients by the PI at the time of their admission to hospice with a review of the clinical assessment in the electronic medical record (EMR). As part of the screening procedures, the PI confirmed demographic data and clinical characteristics including the initial PPS score. The is a valid and reliable prognostic scale that is predictive of the length of survival of terminally ill cancer patients and severity of illness (Downing et al., 2007; Harrold et al., 2005; Moody & McMillan, 2003). Patients who met the eligibility criteria were called by the Quality Assurance assistant and approached for enrollment into the study. If the patient agreed to enrollment, then the PI arranged for a home visit for consent. After the consent/intervention visit with the participant, a separate evaluation with a research nurse over telephone completed

the ACP Survey. The PI kept detailed field notes on the procedures and the observations of this novel intervention.

Study Instruments

There is no published instrument for measuring the likelihood or actual decision making and communication associated with ACP. The Advance Care Planning Survey was constructed from the research findings of the NCCN Palliative Care Guidelines (V.1.2009), the Agency for Healthcare Research and Quality Advance Care Planning: Preferences for Care at the End of Life publication (Kass-Bartelmes, 2003), the 2008 National Hospice and Palliative Care Organization Facts and Figures on Hospice Care in America, and in accordance with the language used in the Texas Advance Directives Act of 1999. The generic words were used on the ACP Survey for a living will, medical power of attorney (surrogate decision maker), and an out of hospital do not resuscitate order. Content and face validity were established by a group of experts within the Texas hospice; the survey was further refined and validated by the experts on the researcher's dissertation supervisory committee. The ACP Survey was pretested with three people diagnosed with cancer; there were no recommendations for change.

There are 22 items on the ACP Survey, including decision making and communication to a surrogate decision-maker for each of the following items: living will, ventilator, oxygen, feeding tube, IV fluids, blood transfusions, antibiotics, surrogate, out of hospital do not resuscitate form, resuscitation, and calling 911. Each item was scored twice, once to indicate whether a decision had been made and once to indicate the degree to which it had been communicated. The ACP Survey was scored on a likert scale with 1 being "not at all likely" and 6 being "done." The word "done" in the ACP Survey is an indication that the consenter had completed the task of decision making or communication. This is a likelihood scale so the likelihood of making a decision and the likelihood of communicating with others. However, it does not mean that the action had been taken.

Two instruments were designed to evaluate the ABM intervention. The first was an open-ended 10-question instrument with an eighth-grade reading level was developed to elicit

participant feedback regarding the intervention's effectiveness, process, outcome, design, and utilization. The second was an observation instrument used by the researcher to evaluate the participant's adherence, receptivity, initiation, prompting, encouragement, flow of memories, overall sense at the end of the ABM intervention, and the amount of time to complete the ABM intervention. The observation instrument was completed immediately following the ABM intervention by the PI.

Data Analysis

Data were entered into the REDCap database at The University of Utah, College of Nursing (Harris et al., 2009) for the 165 potential participants approached for study enrollment, and then data were exported to SPSS 20.0 version for graduate students for statistical analysis using the Excel option in REDCap reports. The PI and research nurse verified the accuracy and completeness of the data in REDCap using visual examination and in the Excel spreadsheet using sorting procedures. Chi squared, t-tests, and Mann-Whitney tests were used as appropriate to compare the control group and the experimental group. Descriptive and inferential analyses were used to analyze the data.

Data analysis plan included two inferential statistics with an independent sample T-test to compare the control group with the experimental group as the initial choice for the ACP Survey and a Mann Whitney U test if the data findings were not meeting assumptions of the independent samples t-test. Researchers planned for an alpha level adjustment to correct for an increased risk of a Type 1 error due to the multiple comparisons with the t-test or the Mann Whitney test (Pett, 1997). By using the global scores for communication and decision making, these two scores limited the adjustment ($\alpha/n = 0.10/2$ or 0.05). Multiple comparison tests for each item in the ACP survey ($\alpha/n = 0.10/22$ or 0.0045), researchers determined that an alpha level of 0.0045 would be too restrictive for this feasibility study and that an alpha level of 0.01 would be conservative enough to avoid finding significance where there is none.

Results

Demographic and Clinical Characteristics

Fifty consenters with terminal cancer completed this study and 115 nonconsenters did not participate in the study but demographic and clinical data were obtained from them as part of the screening process. No statistical differences in demographic information were reported with the larger group of 165 patients; of note was a standard residual of 2.3 with the nonconsenters in the experimental group showed an over representation of a 30% PPS score with 20 observations as compared to the 12 that were expected (see Chapter 4).

A total of 50 participants in the control and experimental groups completed the study with equal numbers in each group. Demographic data and clinical characteristics and statistical analyses were carried out using chi-square, except as indicated (Table 5.2, 5.3). There were no statistically significant differences between the control and experimental groups with respect to age, gender, ethnicity/race, marital status, health insurance, income, level of education, and occupation. Participants in the control group ($n = 25$, $M = 69.4$ years, $SD = 8.5$, range 55 to 85 years) compared to the participants in the experimental group ($n = 25$, $M = 70.5$, $SD = 10.5$, range 55 to 88 years) showed no statistical difference. More than half of the study participants were male (56%), Caucasian (70%), married (54%), and had Medicare (76%). Fifty eight percent had income $> \$25,000$, 44 participants had completed high school/GED or more education (88%), and 30% had retired or stopped working from executive/management/professional careers.

No statistical differences ($p > .10$) occurred between the participants in the control group and the experimental group with respect to PPS score, co-morbid conditions, and length of time from diagnosis to hospice using the chi-square statistical analysis. The two most frequent initial PPS scores for each group was 40% or 50%. Clinical characteristics are summarized in Table 5.3 for participants in the control and experimental groups. The most common cancer diagnoses were lung (26%), pancreas (16%), breast (12%), colon (8%), and prostate (8%), and the most common time frames from diagnosis to hospice enrollment were less than 1 year to 1 year (30%). Cardiac, hypertension, and secondary cancers were the most common co-morbidities for each

group. In addition, the participants' time from diagnosis to hospice enrollment did not differ by group $\chi^2 (1, n = 50) = .86, p = .36$.

ACP Survey and Eligibility Criteria

All 22 variables on the ACP Survey were answered by the participants. Eleven variables were related to decision making for ACP items, and 11 variables were related to communication. Descriptive statistics showed the distributions of all variables (22 in total) are asymmetrical with negatively skewed results. The possible range of item scores were 1 for "not at all likely," 2 for "somewhat unlikely," 3 for "neutral," 4 for "somewhat likely," 5 for "very likely," and 6 for "done." With a possible range for both decision making and communication variables of 1-6, the results showed the obtained range for decision making was 3-5. The obtained range for communication was 2-5.

Following the data analysis plan, inspection of the scores indicated skewness with the majority of the median scores were 6.0; thereby, a nonparametric test was used to analyze the data (Table 5.4). Using Mann-Whitney U test with an alpha level of 0.01 to adjust for multiple comparisons, the experiment group, which had received the ABM intervention, had a higher statistically significant likelihood of communicating about the decision for antibiotics ($U (48) = 211.00, Z = -2.83, p = 0.005$) compared to the control group. There was a meaningful trend toward significance with five other variables: decision making about a feeding tube ($U (48) = 231.00, Z = -1.86, p = 0.063$), IV therapy ($U (48) = 203.00, Z = -2.28, p = 0.023$), and communicating about the decision for a feeding tube ($U (48) = 234.50, Z = -2.37, p = 0.018$), blood ($U (48) = 250.00, Z = -1.68, p = 0.094$), and an Out of Hospital Do Not Resuscitate form ($U (48) = 262.50, Z = -2.06, p = 0.039$).

Study criteria excluded candidates with a living will or a surrogate power of attorney. All the participants in this study had previously been educated on an advance directive by the health-care facility during the work up for cancer and by the hospice team; however, they enrolled into hospice without advance directive (living will or surrogate power of attorney). The first question on the ACP Survey is the likelihood of making a decision about a living will and later on in the

survey is the likelihood of making a decision about a surrogate decision maker. The mean scores for control group and experimental group were 5.12 and 5.16, respectively, for living will and 5.84 and 6.0, respectively, for a surrogate decision maker which showed that participants were “most likely” to “done” with making a decision about both variables (Table 5.4). We know participants did not have these documents by the documentation and verification of the hospice team (admission nurse, RN case manager, social worker, and chaplain) during their initial visit with the patient. The PI confirmed this during the initial visit. Although it is uncertain if the participants ever completed a legally executed living will or a legally designated surrogate power of attorney before they died, it important to recognize that ACP does not require the execution of these documents.

Evaluation of the Intervention by the Participant

Twelve participants agreed to the postintervention evaluation of the ABM intervention conducted by the research nurse (Table 5.5). Fatigue was the reason cited for not participating in the evaluation of the ABM intervention. All participants used at least one positive adjective during the evaluation report. No negative comments were verbalized to the nurse researcher or PI about the ABM intervention. The most common adjectives that participants used to describe the ABM intervention were: easy, enjoyable, nice, and positive. All participants reported to the research nurse that they recalled memories of family and friends who had died during the ABM intervention. All participants said it was easier to talk about health-care decisions when using the ABM intervention; for example, one participant said “It gave us a way to talk about a difficult topic without upsetting my daughters.” All participants shared that it was not difficult to talk about health-care decisions using the ABM intervention, and they did not find the ABM intervention or the recalled memories uncomfortable. No participant had any suggestions or changes for the ABM intervention when asked.

Seven participants found it easier to talk to others about their health-care decisions when using memories from a previous experience. Eleven participants said that other people or family had shared their same memory. Seven participants had spent time using memories to help make

decisions after the ABM intervention. Several participants used the ABM intervention to think about the future, and two of them said “I did talk with my wife about my sister’s death,” and I thought about “what was going to happen to me.”

When asked to name one thing they had learned from this ABM intervention experience, the participants reported a variety of things: “remembering how others died helped me make my own decisions,” “my experiences are helping me,” “all of us have to make decisions,” “it was interesting,” “it was easy to remember,” and it is “always good to learn.”

Evaluation of the Intervention by Research Observation

The observations and data collection made by the PI provided additional evaluative data of the ABM intervention (Table 5.6). All participants ($n = 25$) were able to spontaneously initiate the ABM intervention and were able to adhere to the ABM intervention and complete the postintervention ACP Survey. The majority of the participants ($n = 22$, 88%) reacted positively with the grand tour question by engaging in a narrative about their memories. Three participants neutrally responded to the grand tour question with quiet response before the reply. Most of the participants needed a minimal amount of prompting and encouragement for the ABM intervention. There was an independent, spontaneous flow of narratives from 17 participants. No hesitation, prompting, or encouragement was needed when they answered the ABM intervention questions. For the 9 participants requiring moderate prompting, all required direct verbal prompting, and four participants required deliberate nonverbal gesturing to complete the ABM intervention. Two participants were re-directed back to the topic as they “wandered off topic” and it was “difficult to focus.” One participant was severely hard of hearing, and questions were repeated several times.

The flow of the ABM intervention consisted of four separate evaluative measures. These measures were: whether the memory was related to end-of-life or cancer or both, the number of memories per participant, whether the memories were specific or general in nature, and the subject of the memory, for example, one’s mother (Table 5.7).

All participants ($n = 25$) were able to recall memories related to end-of-life health-care decisions and ACP, the majority of whom ($n = 20$) recalled memories of people with cancer who had succumbed to the disease. Five participants recalled memories of people who had died of a stroke ($n = 3$), from CHF ($n = 1$), and from ALS ($n = 1$). The narrative of the memories varied as well as the number of memories.

A total of 55 memories were recalled by 25 participants. The average number of memories was 1.95, ranging from one to four memories for the 25 participants. Thirteen participants (52%) recalled specific memories; five participants (20%) recalled general memories; seven participants (28%) recalled both specific and general memories. Thirty-nine specific memories were recalled by 20 participants. Specific memories of first-degree relatives, second-degree relatives, and unrelated people accounted for 59%, 15%, and 26% of memories, respectively. The first-degree relatives, mother ($n = 9$), father ($n = 7$), sibling ($n = 5$), and child ($n = 2$), were accounted for 59% of the specific memories. The second-degree relatives, grandparent ($n = 4$) and niece ($n = 2$), accounted for 15% of the specific memories. The unrelated people accounted for 26%, spouse ($n = 3$), in-law ($n = 5$), friend ($n = 1$), and political figure ($n = 1$).

Sixteen general memories of categorical events (i.e., multiple occurrence of the same event) were recalled by 12 participants. Close friends ($n = 8$) who had died accounted for 50% of the general memories; first-degree relatives ($n = 3$), such as mother and sibling, accounted for 19%; second-degree relatives ($n = 3$), such as nephew, aunt, grandmother, accounted for 19%; and patients ($n = 2$) accounted for 12%. The five participants who recalled only general memories also had a lower PPS score of 30 or 40% ($n = 3$), one participant never had a family member or close friend death-related experience, and one participant unexpectedly died 2 days after the interview.

Process outcomes were also measured (Table 5.6). The PI spent between 20 – 90 minutes (an average of 46 minutes) with the 25 participants in the control group and between 25 – 120 minutes (an average of 43 minutes) with the 25 participants in the experimental group. For the attention-control group, the time from introduction to departure was spent on obtaining

demographic data and clinical characteristics. Participants shared details of how their disease was diagnosed. It took an average of 5.6 minutes for participants to give consent in the experimental group, leaving an average of 42.4 minutes of the memory intervention. One factor contributing to the execution of the memory intervention was the participant's willingness to engage in memory recall and answer the researcher's questions. These results corroborated the participant's feedback and the researcher's observation that engaging in the ABM intervention was spontaneous after the grand tour question.

There were no referrals made of psychosocial support or counseling due to the ABM intervention. Recalling memories of people who had cancer at the end-of-their-life was not as emotionally charged as one would expect. Two participants cried about their loss of family during the interview, and both participants gained composure after a few minutes. The memory intervention was completed in one visit.

The study design (Figure 5.1) called for the time between screening to informed consent/intervention to be 5 to 9 days after the hospice admission and the completion of the ACP Survey between Day 10 and 13. In actuality, it took an average of 8.7 and 10 days from screening to informed consent/intervention and 10.1 and 11.7 days for the ACP Survey to be completed for the control and experimental groups, respectively. There was no difference between the two groups with respect to timing set for the study design ($p > .10$).

Discussion

There were 50 participants for this pilot study, which was conducted over a 12-month period. Statistical analysis showed no difference in the participants' demographic and clinical characteristics between independent groups ($p > .10$). The demographics are reflective of the national hospice population statistics (NHPCO, 2012) in terms of gender, ethnicity/race, and insurance. The Palliative Performance Scale was useful as a screening tool for including participants who engaged in conversation and decision making while being cognitively intact. By design, the study excluded people with advance directives, people with HIV, dementia and

Alzheimer's disease, and people who were hospitalized. Future research might consider the study's utility in these groups.

The results of this intervention with participants with terminal cancer show preliminary support that using an ABM intervention will facilitate ACP discussion and decision making. There is no previously published research with which to compare these findings. The intervention may be useful for certain aspects of ACP: decision making about a feeding tube and IV therapy, as well as communicating about the decision for a feeding tube, blood, antibiotics, and an Out of Hospital Do Not Resuscitate form. The findings of these variables trending toward significance may stem from the involvement of the oncology patient during the treatment phase. When patients are receiving cancer therapy and exhibit symptoms of dehydration, anemia, or infection, how involved are patients in the treatment decision making of IV therapy, blood administration, or antibiotics? Most often, IV therapy, blood administration, and antibiotics are interventions presented to the patient as part of the oncologist's plan for cancer treatment. Patients may interpret decisions about these treatments as the responsibility of the oncologist. Some participants seemed genuinely surprised when asked on the ACP Survey about these particular decisions. However, the decisions about a living will, ventilators, oxygen, blood transfusion, antibiotics, surrogate, OOH DNR, resuscitation, and calling 911 did not appear to surprise them and were statistically insignificant ($p > .10$).

All participants in the ABM intervention were asked to recall memories of the 11 variables measured on the ACP Survey. The study did not include a correlation of recalled memories during the ABM intervention with the ACP variables. Correlation analysis of the memories of the specific variables of decision making and communication with the results of the ACP Survey would be a consideration in a future study as it would be useful in determining the direction and strength of the relationship between the ABM intervention and the participant's decision making and communication.

As expected by previous ABM research, participants were able to recall specific memories of family and close friends with cancer who had died by using highly visual cue words (William et al., 2006), and they did this without hesitation. The majority of participants told

narratives about their first- or second-degree family members. They were able to provide more details about the experiences when prompted or encouraged. They were able to complete all steps of the ABM intervention including answering questions about the items in the ACP Survey as it pertained to the family member or close friend who had died. All participants adhered to the ABM intervention and were able to spontaneously initiate the ABM intervention. The study results provided preliminary evidence that the ABM intervention was easy to implement and relatively short in duration. By the participant evaluation, the ABMs and intervention were a non-threatening and comfortable approach to ACP discussions.

A few participants, when asked if they had spent time with using memories to think about the future, said no ($n = 2$, 17%) and not yet ($n = 2$, 17%). The answers to this question may have changed if more time had passed between the ABM intervention and the evaluation. Three participants (25%) did not find it easier to talk to others about your health-care decisions if they used ABM memories, and another two participants (17%) were not sure. From the field notes, the PI and research nurse noted that these participants said they were comfortable with death and dying conversations before the ABM intervention, and the two participants answering not sure had mentioned that they had not tried to recall memories with their family.

The ABM intervention did not cause any injury to the participants, as evidenced by participants' feedback and no psychosocial referrals. The intervention was accomplished in one visit; the participant's feedback indicated that the intervention was easy and enjoyable, and the researcher reported the majority of participants had a positive experience at the end of the session. The results of the ACP Survey triangulated with the participants' feedback and the researchers' observations showed the ABM intervention as a potentially effective means of initiating ACP conversations.

Limitations

This study did have several limitations. This quasi-experimental approach was designed for a comparison of a control with an experimental group that received the intervention. Rigorous

attention to the design of the methods and to the implementation of the procedures was a means of keeping the groups homogenous for comparison and generalization of the results.

Although the ACP Survey instrument was developed from clinical practice standards, input from experts and tested on people with cancer, the instrument had not been tested for reliability or validity prior to this study. A dichotomous scale with yes or no responses for advance care planning variables was too restrictive to measure the degree of decision making and communication. The ACP Survey is a “likelihood” six-response, Likert scale with balanced negative and positive responses. The intent of this scale is to measure how strongly the participant felt about the likelihood of making a decision about the ACP variables according to the two domains of decision making and communication.

The negatively skewed data and the mean range of 4-6 for the ACP Survey for participants in both the control and experimental groups may indicate a ceiling effect. The ceiling effect may be due to several issues or a combination of these issues. Participants who did not have legal documents for advance directives in place at the time of consent may have made or were in the midst of making decisions and communicated about ACP decisions, as indicated by a response of somewhat likely “4”, very likely “5”, or Done “6”. The participants knew they were dying and had prior experience with advance care planning questions since being admitted to hospice. They may not have had the time to decide or communicate these plans or they may have been avoiding the topic. The negatively skewed distribution may be related to the participant’s social desirability of responding with agreeable answers to the research nurse. The left shift could be the instrument design as a Likert-scale and the words of the “likelihood” scale may not discriminate from each other. The combination of the targeted population, in the context of being in hospice with no advance directive, with past experience with end-of-life, and with outward admission that the amount of time to live is limited, may have resulted in the negatively skewed data for ACP Survey for participants in both control and experimental groups.

A reliability analysis was conducted in SPSS version 20.0 on 50 cases to examine the internal consistency of the ACP Survey. Cronbach’s alpha coefficient for the 22 variables was 0.88 and the domains of decision making and communication ranged from 0.80 to 0.85,

respectively. The reported Cronbach's alpha coefficients indicate that the ACP Survey instrument showed good internal consistency. Caution is reserved as this was the initial testing of this instrument.

The participant evaluation and researcher observation instruments were specifically designed for this study. Both instruments will require further testing in future research; the researcher observation will require interrater reliability testing when more than one nurse is facilitating the ABM intervention. Generalization is limited with the small sample size, in a limited population of persons with terminal cancer from one hospice, and the quasi-experimental two-group design.

A potential threat to internal validity for this study consisted of the effect of history on the participant over the 12 months. Copious amount of media attention on The Patient Protection and Affordable Care Act, especially the "death panels" and reimbursement for end-of-life discussions for physicians, surfaced at the end of 2010 as this study was being evaluated at the University of Utah IRB. It is uncertain about these effects since before starting study accrual, the reimbursement of ACP had been removed from the legislation and the media attention had diminished. To control for the effects of participant maturation with ACP as a second threat to internal validity, the PI visited with the participant immediately after the hospice team had completed its visits. The time between consenting and the evaluation of the ACP Survey was concurrent with the original study design and showed no statistical difference ($p > .10$). The time from informed consent/intervention to the ACP Survey ($p > .10$) and the time from admission to the ACP Survey were not significant between the control group and the experimental group using a chi square statistic ($p > .10$).

Details regarding the limitations of conducting a feasibility study have been previously described in Chapter 4. Recruitment and attrition challenges for hospice and palliative care research can be contained by using eligibility criteria that identified participants who can complete an intervention study. All participants in the experimental group talked about end-of-life memories, and it was assumed that people 55 years and older would have at least one death experience and memory of a family member or close friend; however, the PI observed three

participants with general memories of friends with end-of-life experiences. It is possible that people not comfortable with talking about end-of-life experiences did not agree to participate in this study. For the succeeding research trial, the ABM intervention would be modified to include other end-of-life experiences other than family or close friends. A possible alternative would be the death of a well-known celebrity, politician, or business person.

Implications for Practice and Research

This study explored the efficacy and perceptions of an ABM intervention focused on ACP with older persons facing death from cancer. The significance of the study was to provide a reasonable, efficacious intervention to improve decision making and communication of ACP for people with a terminal illness that was congruent with the resolution period at the end-of-life. The conclusion to the current study is that more research is needed with the ABM intervention with a larger and more diverse sample of participants. The importance of this research study laid the groundwork for a future randomized clinical trial using an ABM intervention for ACP for people with cancer and other life-limiting diagnoses.

The ACP Survey requires further evaluation for reliability and validity with a larger group of terminally ill people with cancer. There is no other instrument known to the PI to be used for comparison and psychometric testing. However, the significance of the findings in this study has shown the potential utility of this instrument as a baseline of decision making and communication from which clinicians could begin a conversation of ACP. If the ACP Survey was completed early in the participants' cancer trajectory, participants would then have the luxury of time to make advance care plans and discuss their choices with their oncology nurse, their oncologist, their family, and most importantly their surrogate decision maker. Further research is also needed with the ACP Survey earlier in the patient's cancer trajectory and the resulting outcomes of the advance care planning.

Conclusions

This pilot study provided evidence that directive autobiographical memories influenced the decision making and communication of ACP for a small sample of terminally ill participants with cancer. The results indicated an ABM intervention was spontaneously initiated with minimal prompting or encouragement and no apparent harm inflicted on participants in the ABM intervention. This approach to ACP stimulated decision making and communication with family after the visit ended. An autobiographical memory intervention is not a replacement for ACP education.

The ABM intervention was nonthreatening, was easy to do with the participants as they engaged in this intervention without hesitation, revealed highly personal information of family and friends that had died of cancer, and was completed in less than an hour. When people have the knowledge of ACP but are not ready to make decisions or reconcile these wishes, autobiographical memories of family and close friends provide a safe context for people to think about ACP rather than having them think about themselves. Further research needs to be done to establish ABM as an effective intervention with a larger sample and with participants earlier in the disease trajectory.

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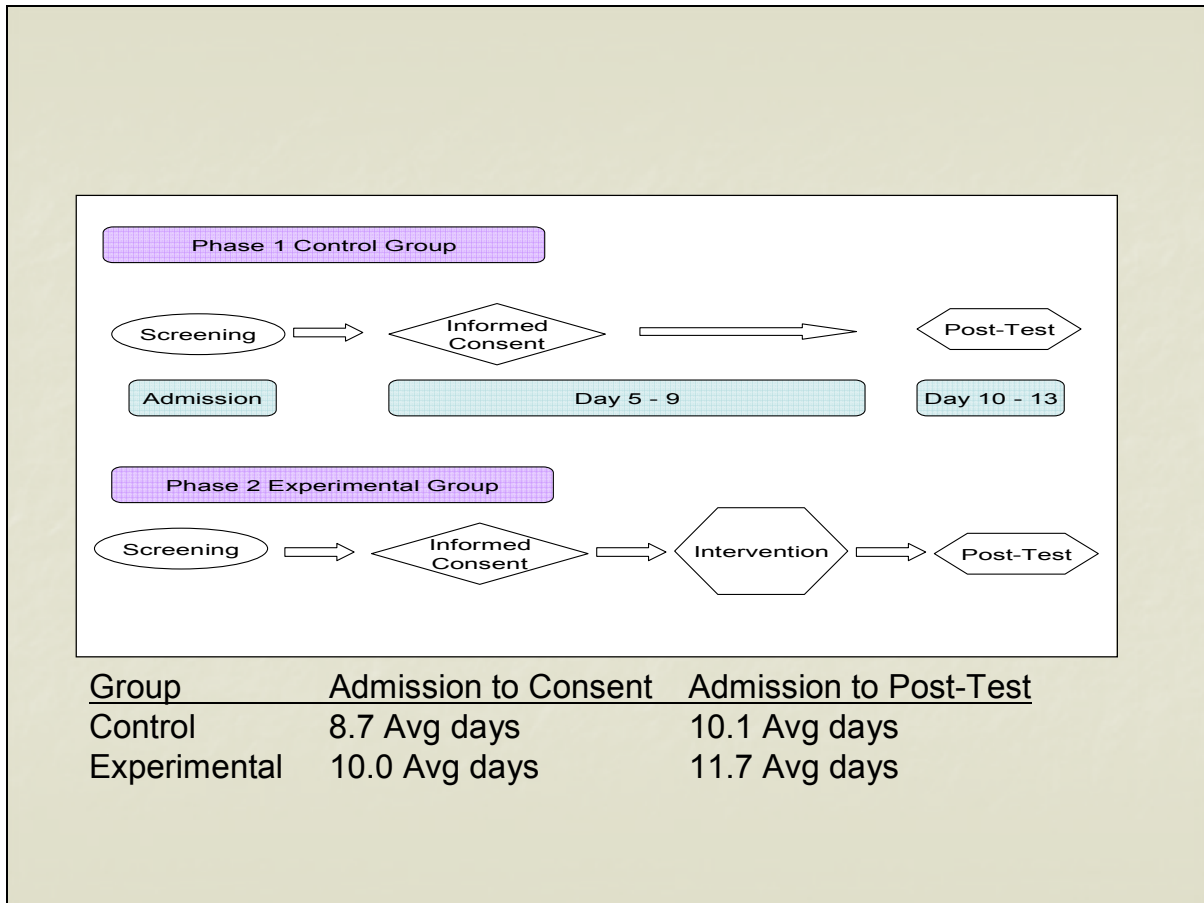


Figure 5.1 Results of the Study Schematic

Table 5.1 Autobiographical Memory Intervention

Stages of the intervention
<p>The Opening</p> <p>After the introduction, the PI confirmed the candidate's study eligibility and proceeded with the informed consent. The consent for the ABM intervention clearly described the intervention.</p>
<p>The Middle</p> <p>The ABM intervention consisted of a highly structured procedure with open-ended questions and talking points to encourage the participant to recall past memories and experiences of family members and close friends with cancer who had died, and their memories with ACP and end-of-life decisions. The script followed a deliberate sequence of non-threatening questions such as demographics and clinical characteristics to more sensitive topics such as the grand tour question of cancer diagnosis and treatment, and then onto to more specific questions about end-of-life decisions. This time enabled the PI to form a bond with the participants, understand their ABMs and how the memories influenced their decision making and communications. Verbal and nonverbal prompting such as nodding or using phrases like "tell me more" were part of the intervention to encourage ABM details. Strict adherence to the script using the intervention checklist and recording of observations using postintervention notes were used as data to evaluate the intervention's efficacy.</p>
<p>The Closing</p> <p>The PI summarized the session and made arrangements for the participant to complete the ACP Survey. The PI was prepared to refer the participant to a social worker or chaplain within the hospice for counseling, but no referrals were made.</p>

Table 5.2 Demographic Characteristics of Control and Experimental Groups

Characteristic	Control group (<i>n</i> = 25) <i>n</i> (%)	Experimental group (<i>n</i> = 25) <i>n</i> (%)	Chi-square (χ^2)
Age			
55-64 yrs	7 (28%)	8 (32%)	<i>t</i> = -.70
65-75 yrs	12 (48%)	6 (24%)	
76 or more yrs	6 (24%)	11 (44%)	
Mean	69.4	70.5	
Median	69.0	72.0	
SD	8.53	10.5	
Range	55-85	55-88	
Gender			.32
Male	15 (60%)	13 (52%)	
Female	10 (40%)	12 (48%)	
Ethnicity/race			.10
Caucasian	18 (72%)	17 (68%)	
All others	7 (28%)	8 (32%)	
Marital status			2.01
Married	16 (64%)	11 (44%)	
Not Married	9 (36%)	14 (56%)	
Insurance			.005
Medicare	19 (76%)	19 (76%)	
All others	6 (24%)	6 (24%)	
Income Range			3.60
< \$25,000	7 (29%)	13 (56%)	
>\$25,000	17 (71%)	10 (44%)	
Education			.74
HS or less	12 (48%)	9 (36%)	
Some college or more	13 (52%)	16 (64%)	
Occupation			2.38
Executive, management, professional	5 (20%) 20 (80%)	10 (40%) 15 (60%)	
All others			

Table 5.3 Clinical Characteristics of Control and Experimental Groups

Characteristic	Control group (<i>n</i> = 25) <i>n</i> (%)	Experimental group (<i>n</i> = 25) <i>n</i> (%)	Chi-square (χ^2)
PPS (Initial)			1.31
Score 60%+	3 (12%)	6 (24%)	
Score 50%	9 (36%)	8 (32%)	
Score 40%	10 (40%)	9 (36%)	
Score 30%	3 (12%)	2 (8%)	
Hospice Cancer			
Diagnosis	6 (24.0%)	7 (28.0%)	
Lung	3 (12.0%)	5 (20.0%)	
Pancreas	1 (4.0%)	3 (12.0%)	
Colon	3 (12.0%)	3 (12.0%)	
Breast	3 (12.0%)	1 (4.0%)	
Prostate	0 (0%)	0 (0%)	
Kidney	1 (4.0%)	0 (0%)	
Ovary	8 (32.0%)	6 (24.0%)	
Other			
Co-morbid condition	39	42	5.76
Length of Time from Diagnosis to Hospice			.86
1 year or less	9 (36%)	6 (24%)	
> 1 year	16 (64%)	19 (76%)	

Table 5.4 Mann Whitney Results for ACP Survey by Group

	Control Group		Experimental Group		Mann-Whitney U Test		
	Mean	Rank	Mean	Rank	MW	Z	p
Decision Making	5.12	25.46	5.16	25.54	311.50	-.023	.981
Living Will							
Communication	5.64	25.08	5.60	25.92	302.00	-.304	.761
Living Will							
Decision Making	5.28	23.40	5.84	27.60	260.00	-1.597	.110
Ventilator							
Communication	5.72	23.96	5.96	27.04	274.00	-1.435	.151
Ventilator							
Decision making	5.72	25.44	5.72	25.56	311.00	-.052	.959
Oxygen							
Communication	5.96	25.52	5.88	25.48	312.00	-.029	.977
Oxygen							
Decision making	4.56	22.24	5.36	28.76	231.00	-1.858	.063
Feeding tube							
Communication Feeding	5.16	22.38	5.94	28.62	234.50	-2.373	.018
tube							
Decision making	4.04	21.12	5.04	29.88	203.00	-2.278	.023
IV therapy							
Communication	5.40	23.46	5.76	27.54	261.50	-1.418	.156
IV therapy							
Decision making	4.84	25.92	4.72	25.08	302.00	-.224	.823
Blood transfusions							
Communication	5.36	23.00	5.76	28.00	250.00	-1.676	.094
Blood transfusions							
Decision making	5.20	24.94	5.32	26.06	298.50	-.323	.747
Antibiotics							
Communication	5.48	21.44	5.96	29.56	211.00	-2.827	.005*
Antibiotics							
Decision making	5.92	26.04	5.72	24.96	299.00	-.504	.615
Surrogate							
Communication	5.84	24.50	6.00	26.50	287.50	-1.429	.153
Surrogate							
Decision making	5.72	26.48	5.52	24.52	288.00	-.745	.456
OOHDNR							
Communication	5.68	23.50	6.00	27.50	262.50	-2.062	.039
OOHDNR							
Decision making	5.60	24.82	5.88	26.18	295.50	-.547	.584
Resuscitation							
Communication	5.88	24.98	5.96	26.02	299.50	-.613	.540
Resuscitation							
Decision making	5.48	24.36	5.80	26.64	284.00	-.868	.386
Calling 911							
Communication	5.60	24.08	5.80	26.92	277.00	-1.323	.186
Calling 911							

- Indicated a statistical significance ($p < .01$)

Table 5.5 Participant Evaluation of ABM Intervention (*n* = 12)

Evaluation Questions and Responses	<i>n</i> (%)
You were asked to recall memories of close family or friends and their health-care decisions.	
Yes	12 (100%)
No	0 (0%)
Was it difficult to talk about health-care decisions before the memory intervention?	
Yes	0 (0%)
No	12 (100%)
Was it easier to talk about health-care decision when using the ABM intervention?	
Yes	12 (100%)
No	0 (0%)
Did you find it easier to talk to others about your health-care decisions if you told them about a previous experience?	
Yes	7 (58%)
No	3 (25%)
Not sure	2 (17%)
Did you spend time using memories to think about the future after the session?	
Yes	7 (58%)
No	2 (17%)
Not yet	2 (17%)
Did not answer	1 (8%)
Name one thing you learned after this experience.	
remembering how others died helped me make my own decisions	
all of us have to make decisions	
how memories impact your life	
always good to learn	
my experiences are helping me	
Would you change this process?	
Yes	0 (0%)
No	12 (100%)
Did anything about recalling memories make you uncomfortable?	
Yes	0 (0%)
No	12 (100%)
Did you find that other people or family members shared your same memories?	
Did you share these memories with others?	
Yes	11 (92%)
No	1 (8%)
Do you have any suggestion after the research experience?	
Yes	0 (0%)
No	12 (100%)
Is there anything else you want us to know?	
Yes	0 (0%)
No	12 (100%)

Table 5.6 Researcher's Observation of ABM Intervention (*n* = 25)

PI Observations	<i>n</i> (%)
Did participant adhere to ABM intervention	
Yes	25 (100%)
No	0 (0%)
Receptivity of the grand tour question	
Positive	22 (88%)
Neutral	3 (12%)
Negative	0 (0%)
Amount of prompting for ABM intervention	
Minimal	17 (68%)
Moderate	8 (32%)
No verbal or nonverbal prompting	11
1- 2 Direct verbal promptings	8
>2 direct verbal promptings	4
Nonverbal gesturing	5
Redirected to topic	1
Amount of encouragement needed for the ABM intervention	
Minimal	17 (68%)
Moderate	8 (32%)
Able to initiate ABM intervention	25 (100%)
Yes	0 (0%)
No	
Overall sense at the end of the ABM intervention on its implementation	
Positive	17 (68%)
Neutral	8 (32%)
Average (range) minutes to complete:	
Control group interview	46 (20 - 90)
Experimental group intervention	43 (25 - 120)
Average minutes for consenting	
Control group	Not applicable
Experimental group	5.6
Average days from admission to informed consent/intervention	
Control group	8.7
Experimental group	10
Average days informed consent/intervention to the ACP Survey	
Control group	1.3
Experimental group	1.6
Average days admission to the ACP Survey	
Control group	10.1
Experimental group	11.7

Table 5.7 Researcher's Observations of ABM Intervention Memories (*n* = 25)

PI Observations of Recalled Memories	<i>n</i> (%)
Specific memories	13 (52%)
General memories	5 (20%)
Both (specific and general memories)	7 (28%)
Specific Memories	39
1 st degree relatives	
Mother	9
Father	7
Sibling	5
Child	2
2 nd degree relatives	
Grandparent	4
Niece	2
Unrelated person	
In-laws	5
Spouse	3
Political figure	1
General memories	16
1 st degree relatives	
Mother	1
Sibling	2
2 nd degree relative	
Grandmother	1
Aunt	1
Nephew	1
Unrelated person(s)	
Friends	
Chemo friends	3
Co-workers	1
Church friends	3
Country club friends	1
Patients	2
Number of psychosocial or counseling referrals	0
Average number of visits to complete the ABM intervention	1.0
Recalled memories for health-care decisions	
End-of-life memories	25 (100%)
Cancer related memories	20 (80%)
Non-cancer related memories	5 (20%)
CHF	1
Stroke	3
ALS	1

CHAPTER 6

SUMMARY AND CONCLUSIONS

Overview of Study and Results

For over 20 years, advance care planning (ACP) has shown little improvement in the completion rate of an advance directive even though it has been researched with people with advanced cancer, chronic debilitating illnesses, various age groups, in numerous settings, and with different disciplines as the facilitator. Instead of using another educational intervention, an intervention from the cognitive behavioral sciences was employed to improve ACP. The autobiographical memory (ABM) intervention uses problem solving, reconciliation, and resolution to rectify end-of-life issues. The purpose of the exploratory, quasi-experimental research was to test the feasibility and efficacy of a novel ABM intervention to promote ACP with older persons terminally ill with cancer in hospice care.

A convenience sample was recruited from the home hospice teams with terminal cancer. Inclusion criteria included the ability to speak and read English, 55 years of age or older, and a Palliative Performance Scale score (PPS) of 30% or higher. Exclusion criteria included diagnoses of HIV, dementia, Alzheimer's disease, or clinical depression and in possession of an executed living will or a medical power of attorney at time of consent. Two independent sample groups (control and experimental) were compared with descriptive and inferential statistical methods.

Data were collected over a 12-month period during the year 2011. Demographic and clinical characteristic data and the ACP Survey provided the quantitative data for analyses, as well as detailed implementation data from the participants' feedback of the ABM intervention

and the researcher's observations of the structure, process, and outcome of participants' engagement in the intervention.

Three general conclusions emerged from this research. The successful completion of the study with no attrition indicates that this type of study is feasible. Utilizing autobiographical memories is an acceptable approach for facilitating decision making and communication with respect to ACP. The ACP Survey shows promise at measuring decision making and communication of ACP.

Study Aims and Findings

Aim 1 Findings and Discussion of the Results

The first aim of the study is to test the feasibility (recruitment, adherence, attrition, logistical issues) of recruiting and retaining hospice patients to this type of study and delivering the ABM intervention for advance care planning with people with cancer enrolled in hospice. The outcome of the feasibility study with hospice patients is summarized and discussed. A description of the four subsets: patients enrolled in hospice during the 12-month period ($n = 1807$), consenters and nonconsenters ($n = 165$), the control and experimental group ($n = 50$), and the experimental group ($n = 25$) are summarized with major discussion points.

Patients Enrolled in Hospice

From January to December 2011, all people electing hospice were screened using the eligibility criteria as depicted in the CONSORT diagram (see Figure 4.2). Of the 1,807 people who were screened for the study, 91% did not meet study inclusion criteria ($n = 1,642$). The specific variables of inclusion criteria not met were: diagnosis other than cancer (56%, $n = 913$) and the remaining (44%, $n = 729$) exhibited signs of uncontrolled physical symptoms and psychological symptoms prohibiting them from participating in the consent process.

Consenters and Nonconsenters

Nine percent of the people electing hospice and screened for the study met the study criteria ($n = 165$). This subset of people, consenters and nonconsenters, was contacted by telephone about the study and agreed to have the Principal Investigator (PI) meet with them. As expected from the literature review and observed during the enrollment of the control group and experimental group, the presentation of uncontrolled physical and psychological symptoms was the prominent reason for ineligibility. Other patient-related issues cited in the literature and found in the group of nonconsenters were “no interest” or refused the study, unable to be contacted by telephone, “too busy to participate” and “too much going on”. Using a chi-square analysis, there were no gender, marital status, ethnicity or race, or insurance differences noted between the consenters and nonconsenters (see Chapter 4, Table 4.1). The nonconsenter in the experimental group ($n = 115$) had a standard residual of 2.3 or an overrepresentation of 30% PPS scores with 20 observations as compared to the 12 that were expected. The PPS was not found to be statistically significant. The importance of having a reliable prognostic tool is clear when conducting an intervention study that requires the consenter’s participation.

Control and Experimental Groups

Thirty percent of the 165 people who agreed to the PI visit were able to consent and complete the study and with no participant attrition. A total of 50 participants completed the study with equal numbers in the control group and the experimental group. Using chi square, there were no statistically significant differences between the two groups with gender, age, race, marital status, education, occupation, income, insurance, PPS, or other clinical characteristics (see Chapter 5, Table 5.2 and 5.3).

Experimental Group

For the experimental group, 87 candidates were approached for enrollment, and of those, 49 candidates did not agree because of the following reasons: unable to contact ($n = 11$), experienced fatigue, pain, or nausea and vomiting ($n = 9$), declined in cognition ($n = 9$), declined

in ADL ($n = 6$), cited “too much going on” ($n = 5$), no interest or refused ($n = 5$), did not understand when the researcher called ($n = 2$), one daughter felt the interview would have been upsetting ($n = 1$), and there was a language barrier with caregiver ($n = 1$). Of the 38 people who agreed, 13 were not able to be enrolled because of the following reasons: decline in cognition ($n = 5$); unable to contact ($n = 5$); experienced fatigue, pain, or nausea and vomiting ($n = 1$); discovered MPOA ($n = 1$); and cited too much going on ($n = 1$). A total of 25 people were approached, agreed, enrolled, and completed the research study in experimental group.

Further Discussion

Hospice and palliative care research has been difficult to conduct due to the overwhelming challenges and barriers to accrual that prevent studies from coming to fruition, yet this population epitomizes the need for ACP research. Researchers continue to explore the traditional educational methods in an attempt to change the outcome of completing the ACP processes.

For this study, a calculated ratio score of 18 represents the number of people needed to be in the initial study pool to have one completed patient; this number compares favorably to the two interventions reported by Hagen and others (2010) in the literature of 83 to 250 NNAs (number needed to assess). A relatively simple calculation to perform provides evidence that the study design is appropriate to the population with practical and minimalistic eligibility criteria and rigorous procedural steps. The reported NNA ratio is an indication of the financial resources and logistical support needed for a larger scale research study.

The combination of access to patient information using the agency's EMR and using the PPS scale to predict prognosis were invaluable screening tools for this study. Both provided up-to-date data on the candidate's physical and psychological status. Simplifying the study procedures with an energy-conserving consent process and waiting a 5 day window after the hospice team had completed their initial comprehensive assessments were effective strategies in approaching previously identified study accrual barriers.

Aim 2 Findings and Discussion of the Results

The second aim of this study was to examine the efficacy of the ABM intervention on specific aspects of advance care planning (i.e., do not resuscitate, use of a breathing tube, feeding tube, use of antibiotics) for people with cancer. The outcome of efficacy of an ABM intervention on ACP is summarized in three sections, participant evaluation of ABM, PI observation, and statistical analysis of the ACP Survey.

Participant Evaluation of ABM Intervention

This study provided the first evidence that an autobiographical memory intervention for ACP can be used with people, 55 years and older, with terminally ill cancer. All participants engaged in the ABM intervention. The majority of participants (88%) responded positively to the grand tour question about autobiographical memories of family or friends with cancer. All participants recalled autobiographical memories of end-of-life for family or friends. Participant feedback showed the ABM intervention was easy to do, quick, caused no harm, and stimulated more discussion with family about health-care decisions.

PI Observation of the ABM Intervention

The PI observations corroborated the results of the participant's feedback and demonstrate the previous research findings of hierarchical specificity of ABM, types of memories (cancer and end-of-life), prompting of ABM, and the statistical findings. A total of 55 memories were recalled by 25 participants. The average number of memories was 1.95, ranging from one to four memories for the 25 participants. Thirteen participants (52%) recalled specific memories; 5 participants (20%) recalled general memories; 7 participants (28%) recalled both specific and general memories. This confirms the value of using instructions on specificity and hierarchical memories for categorization.

Statistical Analysis of the ACP Survey

The study plan for the statistical analysis to compare two independent groups called for the chi square and t-test. Unfortunately, the t-test assumptions of a normal distribution of results were not met, as participants in this study had made most decisions related to advance care planning and had communicated these decisions to their surrogate decisions maker.

Following the data analysis plan, inspection of the scores indicated skewness with the majority of the median scores were 6.0; thereby, a nonparametric test was used to analyze the data (Table 5.4). Using Mann-Whitney U test with an alpha level of 0.01 to adjust for multiple comparisons, the experiment group, which had received the ABM intervention, had a higher statistically significant likelihood of communicating about the decision for antibiotics ($U(48) = 211.00, Z = -2.83, p = 0.005$) compared to the control group. There was a meaningful trend toward significance with five other variables: decision making about a feeding tube ($U(48) = 231.00, Z = -1.86, p = 0.063$), IV therapy ($U(48) = 203.00, Z = -2.28, p = 0.023$), and communicating about the decision for a feeding tube ($U(48) = 234.50, Z = -2.37, p = 0.018$), blood ($U(48) = 250.00, Z = -1.68, p = 0.094$), and an Out of Hospital Do Not Resuscitate form ($U(48) = 262.50, Z = -2.06, p = 0.039$).

Traditionally with cancer treatment, IV therapy, blood administration, and antibiotics are presented to the patient as part of the plan for cancer treatment. Patients may have interpreted this approach as not being involved in the decision making process but rather the recipient of the decision. Whereas, questions regarding ventilation, resuscitation, calling 911, surrogate decision making, and oxygen are common and expected during the hospice admission process.

The total sum of the 11 decision making variables was calculated into one global score for decision making for each participant; the same calculation was done for a global score for 11 communication variables for each participant (Table 6.1). The global scores for the ACP Survey were statistically analyzed using the Mann-Whitney statistic due to the non-normal distribution (de Winter & Dodou, 2010); an adjustment for multiple comparison was made to the 0.10 alpha level and set at ($\alpha = .05$) by dividing the alpha by two. The Mann Whitney U test showed no

statistically significant difference between the experimental and control group for global decision making, ($U = 222.50$, $Z = -1.77$, $p = .08$) but it did show statistical significance for global communication ($U = 180.50$, $Z = -2.94$, $p = .003$). The mean ranks of the experimental group for both global scores were higher than the mean ranks of the control group and so the experimental group has a higher mean global score for both decision making and communication than the control group.

This dissertation was a pilot study designed for the purpose of testing the novel intervention on the decision making and communication domains of ACP. Capitalizing on the work of health-care professional to educate the participants on ACP, the ABM intervention guided the participants to use the memories of end-of-life experiences with family and close friends to direct the decisions and communications of their present hospice enrollment.

Implications for Practice

The knowledge gained in this study adds to our understanding of autobiographical memory as a directive function with people at the end-of-life and our understanding of advance care planning. Nurses are in a unique position to interact with people with cancer across the cancer continuum of care. From the time of diagnosis until survivorship or hospice comes to pass, the oncology nurse and advance practice nurse are knowledgeable that education alone or possessing a legal advance directive is not the answer because they fall short of the goals of advance care planning. A more sensitive and compassionate approach to the topic of advance care planning is the use of memories of familiar people, who have made their way through the end-of-life journey, to help our patients with their current situation of facing their death and making their preferences and wishes known. Autobiographical memories used in a directive function have shown promise in influencing the current situation from past experiences with respect to ACP.

The PPS score is not only a practical and predictive instrument for prognosis for people with cancer, but it is also an excellent tool for determining the amount of nursing resources to care for people at the end-of-life. It can be used as an abbreviated language to the hospice

interdisciplinary team on the patient's length of survival and how quickly the team needs to complete a comprehensive assessment. The PPS score is a quick and easy scale to explain to family members when conveying the imminence of death; in other words, a PPS of 10% is recognized as close to death.

The PPS score was also shown, in this study, to be a reliable and excellent scale to screen hospice patients for this intervention research study and to exclude people who were likely not able to participate in the intervention. The PPS is reflective of where the patient is along the dying trajectory and would be a helpful screening tool when enrolling caregivers into a hospice study. For the patients who were not enrolled in this study, there was indication from the caregivers that the PPS had dropped based on their description, thus making the patient ineligible for the study. When the functional status of the patient declines, the opposite effect happens with the caregiver; his or her workload and strain increases.

The PPS is an example of when practice and research are intertwined. The accuracy of the PPS score depends on clinician experience and expertise. If the hospice agency does not have a competency-based education program for the nurses, then an opportunity for the researcher to test their reliability against scripted scenarios on an annual basis and upon employment will be important for the researcher. Another means of establishing reliability of the PPS could be accomplished through a systematic evaluation and comparison of the admission nurse and the medical directors of the hospice to ensure accurate PPS scores. An inter-rater reliability program was established at this hospice and was not an identified problem in this study. The PPS is not a new instrument, but its use as part of the eligibility inclusion criteria and outcome measurement in the literature is limited. Researchers should consider this scale when engaging hospice and palliative care patients or caregivers in research.

Implications for Research

This pilot study provided the researchers and the agency an opportunity to become familiar with each other and to explore possible opportunities for shared clinical care and research implementation to improve outcomes in hospice populations. Researchers working in

the hospice and palliative care field require close, “insider” relationships within the organization to complete a successful research study. Ordinarily, the researchers are outsiders to the hospice agency from which patients will be accrued, and a pilot study gives the researcher the perfect opportunity to establish credibility. During the pilot study, a researcher can learn about the internal processes of the hospice including the medical recordkeeping; the competency-based education and training of the interdisciplinary team members, directly or indirectly, involved in the pilot study; and the type of patients enrolled into the hospice setting.

One of the most important processes for researchers to understand in a patient-focused intervention study as this one is the notification of hospice clinicians of the patient’s uncontrolled symptoms. It is imperative to the researcher to have contact with those who have the most recent relevant clinical report on the patient’s status. Experienced and knowledgeable researchers in hospice research will recognize the presentation of an end-of-life symptom specific to the patient’s cancer and understand the transition period preceding death and the patient’s ability to participate in the study. Being an insider to the organization presented mostly positive outcomes for the study, with access to the EMR, interdisciplinary team (IDT), patient care manager, and hospice medical director. As an outsider, the experienced researcher should not assume that his or her years of hospice research or study outcomes are well-known and should make every effort to establish his or her credibility by giving back to the organization their expertise in the form of an educational offering or shadowing the hospice employees to gain insight into the processes. Confirmation that the researcher had established credibility and the study was accepted by the IDT was evident when clinicians continued to refer patients to the study months after it had ended.

Completing this feasibility study was preparation work for further research on autobiographical memory and advance care planning. The researcher was afforded the privilege of testing procedures, criteria, interventions, and evaluation tools in preparation for conducting a large-scale research study. The results of this feasibility study showed promise that ABM intervention positively impacts decision making and communication for some aspects of advance

care planning. The researcher's speculation that an ABM intervention may be conducted by other disciplines besides nursing but this option would need to be evaluated in future research.

The ACP Survey is a scale of the likelihood of making a decision and likelihood of communicating that decision. No other survey has been found in the literature for advance care planning. Although the study was done in Texas, the ACP Survey contains words and phrases, such as out of hospital do not resuscitate, that are common terms used with advance directive and applicable across the US. It is expected that as the patient with cancer progresses through the cancer trajectory of diagnosis, workup, treatment, cure and survivorship, and/or progression/recurrence and hospice that the ACP Survey scores would change. Further study is needed for establishing reliability and validity, testing on a larger sample of people with cancer, and measuring the changes with the ACP Survey over the patient's cancer trajectory.

Implications for Theory Building

Few articles reference Singer's Advance Care Planning Model from its original publication in 1998, but this is the only model of ACP and depicts common and uncommon pathways of ACP. Like the model, this study considered the influential antecedents of ACP to be a terminal diagnosis of cancer and prior education on the advance directive. Our eligibility criteria positioned this study at the point of "inaction," meaning that no advance directive was completed and there was no surrogate decision making named.

The results of this study using an ABM intervention lead to additional pathways on the model (Figure 6.1). The most interesting and applicable pathway with respect is a nonexistent path leading from "inaction" to the event box labeled "informing proxy." Further research is needed to confirm the existing pathways on the model and ways to move from "inaction" to action.

Implications for Policy

The Dartmouth Atlas of Health Care project reviewed over 235,000 hospital medical records for patients with cancer from 2003 – 2008 (Skinner, Gottlieb, & Carmichael, 2011). One

third of the patients died in the hospital (7-47%), 6-10% received chemotherapy, and another 4-18% received life-sustaining interventions (feeding tube or cardiopulmonary resuscitation) during the last two weeks of life. Obvious to the facts performing life-sustaining interventions was the need for better prognostic tools and better decision making and communication with advance care planning, and doing so without scaring people that their autonomy for health-care decisions would be taken away or decided by an independent panel.

Facing one's mortality and talking about death, whether imminent or years off, are not easy. The population in the United States is aging, living longer, and getting larger. Today, the aging Baby Boomers find themselves at risk for cancer, as 80% of cancers are diagnosed in people over the age of 65 (American Cancer Society, 2012). The need for decision making and communication with health-care decision is great. The boomers diagnosed with terminal cancer may have served as surrogate decision makers to their elderly parents and want to pass on a new legacy to the generation that follows but find it hard to talk about their end-of-life wishes. The autobiographical memory intervention can fill this void. When people have the knowledge of ACP but are not ready to make decisions or reconcile these wishes, autobiographical memories of family and close friends provide a safe context for people to think about ACP rather than having them think about themselves.

The ACP Survey combined with the autobiographical memory gives the patient many options to talk about these decisions with his or her family. Using this type of survey as a non-threatening survey is an alternative to previous proposed advance care planning legislation. Its completion by the patient at the time of a cancer diagnosis will help the primary care physician, the cancer surgeon, and the medical oncologist understand the likelihood that decisions have been made. The ACP Survey could serve as a motivator to complete ACP and advance directives and improve the physician-patient communication about ACP, and it could decrease health-care expenditures.

Limitations

Limitations for the study include the quasi-experimental design, the targeted population and intervention including the instruments. The quasi-experimental design was proposed as a means of comparing a control and experimental group without the burden of randomization. A randomization design with a wait-control was not feasible due to the short length of survival in the hospice setting. A prospective study design is the best strategy for conducting a feasibility and efficacy pilot using an original intervention for advance care planning, but there were limitations. Few studies report hospice patients as the target research population because of the nature and complexity of the population. This is the unique study using a convenience group of people with cancer enrolled in hospice for ACP research; the sample is small, and there was one hospice agency. Generalization is limited with the small sample size, in a limited population of persons with terminal cancer from one hospice, and the quasi-experimental two-group design.

The ABM is a novel and untested intervention with a large group of participants. Although directive ABM provides a defensible approach to problem solving and adaptation, the ABM intervention is not commonly used in this population and for advance care planning. Some participants lacked a personal death experience with family members or close friends, which presented a study limitation. New instruments for measuring advance care planning and for the autobiographical memory evaluation have not been tested for reliability or validity.

Conclusions

There is only one chance to “get it right” with people who are dying and their families/close others. This study provided a reasonable and effective cognitive behavioral intervention that was sensitive to the end-of-life context while being non-burdensome, non-threatening, and brief in duration. The ABM intervention was a catalyst to make decisions and communicate about certain end-of-life wishes.

The study improved decision making and communication with some aspects of advance care planning. The autobiographical memory intervention left a legacy for the family on how to die in hospice with dignity and respect. The importance of this research study is to lay the

groundwork for a future randomized clinical trial using an ABM intervention for advance care planning for people with cancer. The larger significance of this research work is to provide an effective means to improve advance care planning and improve the quality of outcomes for patients at the end of life.

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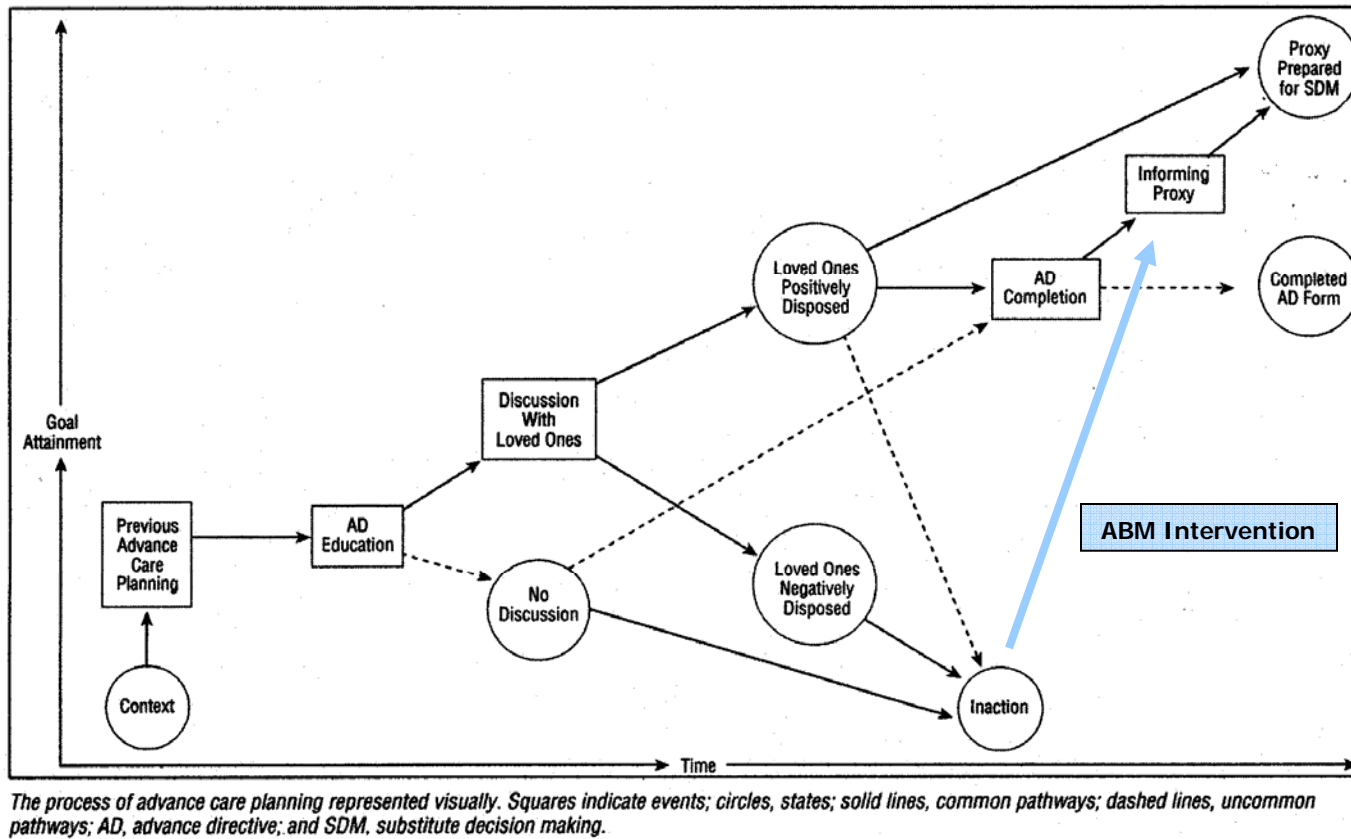


Figure 6.1. Advance Care Planning Model with Modifications (originally developed by Singer et al., 1998) and published with permission from Dr. Singer with modifications.

Table 6.1 Mann-Whitney U for Global Scores for ACP Survey

Global Score	Control group		Experimental group		<i>Mann-Whitney</i>		
	Mean	SD	Mean	SD	<i>MW</i>	<i>Z</i>	<i>p</i>
Decision Making	57.68	6.92	60.28	7.70	222.50	-1.77	.076
Communication	61.52	7.06	64.64	3.95	180.50	-2.94	.003*

*Indicated a statistical significance ($p < .05$)

APPENDIX A

ADVANCE CARE PLANNING STUDY SCREENING CHECKLIST

The purpose of this study is to understand health-care decisions that are made by people enrolled in hospice.

Patients are eligible if they are:

Yes	No	Criteria
<input type="checkbox"/>	<input type="checkbox"/>	Patient is diagnosed with terminal cancer
<input type="checkbox"/>	<input type="checkbox"/>	Patient is receiving hospice home care
<input type="checkbox"/>	<input type="checkbox"/>	Patient is able to speak and read English
<input type="checkbox"/>	<input type="checkbox"/>	Patient is 55 years old or older
<input type="checkbox"/>	<input type="checkbox"/>	Patient is cognitively intact
<input type="checkbox"/>	<input type="checkbox"/>	Palliative performance score is 30% or higher

Patients are excluded if on admission to hospice they are:

Yes	No	
<input type="checkbox"/>	<input type="checkbox"/>	Diagnosed with HIV, dementia, or Alzheimer's disease
<input type="checkbox"/>	<input type="checkbox"/>	Hospitalized or in the IPU
<input type="checkbox"/>	<input type="checkbox"/>	Have a living will or a medical power of attorney

APPENDIX B

CHECKLIST FOR STUDY SCREENING THROUGH CLOSURE

	<u>Yes</u>	<u>No</u>	<u>Procedural Steps</u>
Screening and Recruitment (Day 1-5)			
1.	<input type="checkbox"/>	<input type="checkbox"/>	Screening complete
2.	<input type="checkbox"/>	<input type="checkbox"/>	Patient meets criteria:
Consent and Intervention Session(s) (Day 5-9)			
3.	<input type="checkbox"/>	<input type="checkbox"/>	Interview scheduled between _____ (D5 – D9)
4.	<input type="checkbox"/>	<input type="checkbox"/>	Take recording equipment for Phase 2 ABM intervention
5.	<input type="checkbox"/>	<input type="checkbox"/>	Consent signed (take 2 copies, leave 1 with participant)
6.	<input type="checkbox"/>	<input type="checkbox"/>	Demographic and Clinical Information collected
ABM Intervention for ABM participants only (Day 5-9)			
7.	<input type="checkbox"/>	<input type="checkbox"/>	Ask if he/she needs a break or can talk longer
8.	<input type="checkbox"/>	<input type="checkbox"/>	Ask a grand tour question
9.	<input type="checkbox"/>	<input type="checkbox"/>	Prompting (if needed)
10.	<input type="checkbox"/>	<input type="checkbox"/>	Tell me about an experience with the ACP Survey variables Will you make any changes in your health-care decisions?
11.	<input type="checkbox"/>	<input type="checkbox"/>	Summarize the intervention session
12.	<input type="checkbox"/>	<input type="checkbox"/>	Give study business card and thank you
13.	<input type="checkbox"/>	<input type="checkbox"/>	Offer referral for advance directive or psychosocial support
14.	<input type="checkbox"/>	<input type="checkbox"/>	Schedule survey & intervention evaluation for __ (D10 – 13)
15.	<input type="checkbox"/>	<input type="checkbox"/>	PI completed Observation Survey
Advance Care Planning Survey Administration (Day 10-13)			
16.	<input type="checkbox"/>	<input type="checkbox"/>	Complete Advance Care Planning Survey
Postintervention Evaluation Interview for ABM participants only (Day 10-13)			
17.	<input type="checkbox"/>	<input type="checkbox"/>	Invite participant to evaluation ABM Intervention
18.	<input type="checkbox"/>	<input type="checkbox"/>	Complete Postintervention Evaluation Interview as indicated
Data Entry (Day 14-15)			
19.	<input type="checkbox"/>	<input type="checkbox"/>	PI confirms completion for the survey
20.	<input type="checkbox"/>	<input type="checkbox"/>	Send thank you note from PI and gratuity

APPENDIX C

POSTINTERVENTION EVALUATION INTERVIEW FOR ABM

Participant's Name _____ Date _____

Please ask the following questions about the ABM intervention:

1. Tell me about your experience with the nurse researcher. You were asked to recall memories of close family or friends and their health-care decisions.
2. Was it difficult to talk about health-care decisions before the memory intervention?
3. Was it easier to talk about health-care decision when using the memory intervention?
4. Did you find it easier to talk to others about your health-care decisions if you told them about a previous experience?
5. Did you spend time using memories to think about the future after the session?
6. Name one thing you learned after this experience.
7. How would you change this process?
8. Did anything about the recalling memories that made you uncomfortable?
9. Did you find that other people or family members shared your same memories? Did you enjoy sharing these memories with others?
10. Do you have any suggestion after the research experience?
11. Is there anything else you want us to know?

APPENDIX D

ADVANCE CARE PLANNING SURVEY

Name _____ Date _____

Who is your designated health-care decision maker? _____

Please answer these questions. Circle the one number that best describes your answer.

1	2	3	4	5	6
Not at all likely	Somewhat unlikely	Neutral	Somewhat likely	Very likely	Done

1. What is the likelihood of making a decision about a living will?
2. What is the likelihood of telling your health-care decision maker about your decision about a living will?
3. What is the likelihood of making a decision about a breathing machine (respirator, ventilator)?
4. What is the likelihood of telling your health-care decision maker about your decision on a breathing machine?
5. What is the likelihood of making a decision about oxygen?
6. What is the likelihood of telling your health-care decision maker about your decision about oxygen?
7. What is the likelihood of making a decision about a feeding tube?
8. What is the likelihood of telling your health-care decision maker about your decision on a feeding tube?
9. What is the likelihood of making a decision about IV fluids?
10. What is the likelihood of telling your health-care decision maker about your decision on IV fluids?
11. What is the likelihood of making a decision about a blood transfusion?
12. What is the likelihood of telling your health-care decision maker about your decision on a blood transfusion?
13. What is the likelihood of making a decision about antibiotics?
14. What is the likelihood of telling your health-care decision maker about your decision on antibiotics?
15. What is the likelihood of making a decision about a person in charge of your health-care if you cannot make decisions?
16. What is the likelihood of telling your health-care decision maker about your decision on a person in charge of your health-care if you cannot make decisions?
17. What is the likelihood of making a decision about an Out of hospital Do Not Resuscitate Order form?
18. What is the likelihood of telling your health-care decision maker about your decision on an Out of hospital Do Not Resuscitate Order form?
19. What is the likelihood of making a decision about your wishes for resuscitation?
20. What is the likelihood of telling your health-care decision maker about your wishes for resuscitation?
21. What is the likelihood of making a decision about your wishes about calling 911?
22. What is the likelihood of telling your health-care decision maker about your wishes about calling 911 in an emergency?

APPENDIX E

THANK YOU LETTER FOR STUDY PARTICIPATION

Month, Date, 2011

Participant Name
Address
Houston, TX 770??

Dear _____ (Participant First Name),

I want to like to extend a sincere thank you for participating in the research study “The Feasibility and Efficacy of an Autobiographical Memory Intervention on Advance care Planning with People with Terminal Cancer.” The study would not have been such a success without your willingness to enroll and participate. I appreciate your time, energy, and willingness to share. It was a pleasure to meet you and your family. Please accept this token of appreciation.

Again, thank you for taking part in our study. I hope you found the experience valuable.

Warmest regards,

Cheryl Brohard, MSN RN AOCN®
Doctoral Nursing Student, University of Utah
11626 Cherryknoll Drive
Houston, TX 77077-5010